DOCTOR OF PHILOSOPHY

Transition or transfer? An experiential perspective on moving from paediatric to adult cancer services

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Table of Abbreviations

Abbreviation	Meaning
ALL	Acute Lymphoblastic Leukaemia
CCG	Children's Cancer Group
CNS	Clinical Nurse Specialist
HCP	Health Care Professional
JIA	Juvenile Idiopathic Arthritis
LTFU	Long-Term Follow-Up
NHS NPSA	NHS National Patient Safety Agency
POG	Paediatric Oncology Group
TYA	Teenagers and Young Adults
UKCCSG	United Kingdom Children's Cancer Study Group

Glossary

Chapters 6, 7, and 8 include quotes from participants in this study. Participants were interviewed from across Scotland; many participants spoke in their local dialect and used common Scottish words throughout. However, recognising that translation of these Scots words into English may be difficult for some, a glossary of the most common words used in these interviews is provided below, to aid the reading experience for those readers not familiar with such terminology.

Scots Term	**English Translation**	**Scots Term**	**English Translation**
aboot	about	**kinda**	kind of
aw	all	**naw**	no
awright	alright	**no**	not
aye	yes	**oh**	of
coudna	couldn't	**ma**	my
dae	do	**maist**	most
dinnae	don't	**wee**	small
fae	from	**wi**	with
fur	for	**wisnae**	wasn't
gonnae	going to	**wid**	would
hame	home	**wis**	was
hersel	herself	**yae**	you

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through the good and bad times but never once doubted my abilities: I can, I will, I am. Jess, you have been on the end of the phone at all the right times and always brightened even the hardest days with something to make me smile. To my close friends Shauna and Susan, you both too have given me great strength over the past few years; probably more than you will ever know. Finally, to those I have been unable to mention personally here; I apologise. But please know this, your support has meant so much to me.

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Declaration

I declare that I am the author of this doctoral thesis, that all references cited have been consulted by me, that the work presented here has been carried out by me and that it has not been previously accepted for a higher degree.

Signature ……

Date ……

Lisa McCann

Abstract

This thesis explores the experiences of young people who are survivors of childhood cancer, their parents, health care professionals (HCPs), and case note documentation, of the process of transition from paediatric to adult cancer services. A qualitative, collective case study approach (Stake, 1995), informed by a constructivist-interpretive position, allowed exploration of the multiple realities prioritised in this study. Whilst there is a significant body of literature relating to transition for conditions such as rheumatology and cystic fibrosis, there is little research undertaken into transition in a cancer context, specifically so from an experiences perspective. This study aimed to re-address this issue.

The experiences of twelve young people were explored in this study. This resulted in the participation of twelve cases, meaning a total of 35 individual, semi-structured interviews were conducted with young people, parents and HCPs. Young people's case notes (22 sets) were also reviewed. Data were analysed using matrix-based approaches advocated by Miles and Huberman (1994), at both the within- and between-case level. This generated a multi-dimensional and multiple perspective understanding of the experience of the process of transition.

The results of this study clearly identified a central orienting theme: The experience of readiness in the context of transition. Three main themes and six sub-themes were also identified within the data, supporting the explanatory power of the orienting theme. The main themes identified were: The experience of childhood cancer; Planning and preparation: Transition or transfer?; and A process of change.

The findings demonstrate that understanding the multi-faceted components of readiness is crucial in understanding people's experiences of readiness. Readiness should embody people's illness experiences, the numerous and associated losses intertwined with a move from paediatric to adult care and the simultaneous developmental changes occurring in people's lives. Only by doing so shall a meaningful

understanding of the experience of the process of transition for survivors of childhood cancer, their parents and health care professionals be developed.

The thesis concludes by making recommendations for future research and clinical practice.

Chapter 1 Introduction

1.1 Rationale for thesis

"They asked me which child was mine." This is what a 21-year-old young man called Douglas told me about his latter years' experiences of his long-term follow-up appointments at his paediatric hospital. He recalled, both with some emotion and frustration, how parents of small children at the paediatric oncology outpatient clinics would often assume he was the father of one of the small children playing at the table, hence his quote. He was in fact in the waiting area of the paediatric outpatient clinic to attend his own long-term follow-up appointment, having been diagnosed with leukaemia when he was 12 years old. However, repeatedly explaining this reason for his attendance to parents in these waiting areas heightened his awareness of just how out of place he felt in that setting. Eventually, interactions such as these and his increasing feelings of standing out in such an environment, prompted him to request follow-up elsewhere; thus he talked to me of his transition to the adult sector.

Douglas's transition, his account revealed, in all actuality, consisted of his attendance at the paediatric hospital stopping, following his request, and simply beginning a year later at his local adult service. It was as abrupt as that. He received no information about the adult service, he was engaged in no formal planning and preparation processes, and he did not have the opportunity to attend the adult service informally prior to his first visit. He was, in effect, simply transferred to an entirely new environment.

Yet, Douglas's experiences were not uncommon. Some years ago, I met regularly with a number of young people affected by cancer who attended a pre-existing support group; I attended in a research advisory capacity as this group volunteered for such involvement. Douglas was a member of this group, so too were Gary and Craig. Both Gary and Craig also shared a number of their experiences with me, and it emerged that their experiences of transition were far from ideal from their perspective. Craig also talked to me about his experiences of attending paediatric care for his routine long-

term follow-up appointments, before being told, at what actually transpired to be his last appointment there, that he was to attend the adult oncology centre the next year. Unlike Douglas, Craig had not requested such a move, but similar to Douglas's experience, there had been no actual discussion surrounding the realities of this. Gary's introduction to adult care was, on the other hand, more stark: admitted for surgery to remove a brain tumour, he left for the operation from the paediatric ward, but awoke from his operation in a different area of the hospital in an adult ward, with male patients much older than he.

Throughout all of these conversations, I was struck by the ways in which all three young men, and others in the group, spoke about their experiences within the paediatric oncology sector. All held the hospital itself and the paediatric oncology teams with such high regard, and Craig particularly talked with great pride about how he still kept in touch with his paediatric nursing team, even though he had been attending adult care for six years at the time of our conversation. Thus, these young people's experiences captured my attention, with my enthusiasm to learn more about experiences such as these heightened by my long-standing concurrent interests and experiences of working with young people and my cancer care research career to that point. The experiences I learned about in these advisory conversations became my intellectual building blocks for developing my PhD proposal. These issues, therefore, led me to consider the experience of making the transition from the paediatric to the adult cancer sector in more depth and detail. Based on my advisory conversations, I was particularly keen to ensure that any project I developed would both honour people's experiences and have the potential to make a positive impact within clinical practice.

Thus, as a researcher, issues surrounding paediatric and young people's cancer care are of particular interest to me. These interests, however, did not derive directly from personal experience – I was not diagnosed with cancer as a child, so the identity of being a survivor of childhood cancer was, therefore, not something I shared with the young people I interviewed in this study. However, my own academic background in psychology and my desire and interest to work with young people both professionally

and in a voluntary capacity, further cemented my interest in this area. Likewise, in terms of identity and positioning, an identity I did not share with the friend or family member participants was that of being a parent, but I believe this not to be a barrier in this study as I prioritised their experiences over mine.

Whilst the wider literature indicated that transition was a topic and an issue that had received increasing attention over the years, due primarily to the rapid increases in survivorship in conditions that were initially considered fatal in childhood (While *et al.*, 2004; Stam *et al.*, 2006), much of the evidence base was primarily focused on chronic conditions, including diabetes (Fleming *et al.*, 2002), rheumatology (McDonagh *et al.*, 2000; Shaw *et al.*, 2004b; McDonagh, 2005; Shaw *et al.*, 2006a), or cystic fibrosis (Brumfield and Lansbury, 2004; Craig *et al.*, 2007). It was noted that although nearly 80% of children diagnosed with cancer achieve cure (Freyer *et al.,* 2006), and although survivors of childhood cancer face a range of potential long-term morbidity risks due to their cancers and the treatments they receive (Scottish Intercollegiate Guidelines Network, 2004), cancer received relatively little attention within transition literature by comparison (Viner, 2003; Viner and Barker, 2005).

For the purposes of this thesis, existing and accepted definitions of transition have been adopted. Whilst a fuller examination of these definitions is explicated in Chapter 3, it is important for contextual purposes to outline the adopted definition here. Thus, in this study, the following accepted definition of transition, coined almost two decades ago, provided the framework for this study:

> *A purposeful, planned process that addresses the medical, psychological and educational/vocational needs of adolescents and young adults with chronic and medical conditions as they move from child-centred to adult-orientated health care systems.* (Blum *et al.*, 1993 p.570)

Within the body of evidence underpinning this definition, from a cancer perspective certainly, the focus was on the development and provision of appropriate long-term follow-up care services (MacLean *et al.*, 1996; Oeffinger *et al.*, 1998; Hobbie and Ogle,

2001; Hudson, 2005). There was a notable lack of experience-based research, particularly regarding the experiences of young people of the process of transition from paediatric to adult cancer services. Yet, as the young people I consulted with in an advisory capacity indicated to me, their transition, or in reality, their transfer (particularly when considered in the context of the definition of transition cited previously) to adult care was a significant element of their entire childhood cancer experience. Therefore, I believed that there was a need to conduct a study on transition which: a) prioritised patient experience; b) considered transition from the perspective of survivors of childhood cancer; and c) considered the transition experience from multiple perspectives. I decided I could make a novel contribution to knowledge by prioritising these three key issues.

To do this, I elected to adopt a qualitative case study based approach. Details of this approach are discussed in greater depth and detail in Chapter 4, but, having decided to use a qualitative approach to explore people's experiences of transition, the decision to adopt a case study based approach was informed collectively by the adopted epistemological positioning and the research question posited. First, the adopted epistemological stance and belief about knowledge meant I was concerned with not only the multiple realties that exist, but so, too, the ways in which these multiple reality constructions influence people's lives (Patton, 2002; Galvin, 2005). Second, as the posited research question was concerned with the experience of transition not only from the patient perspective, but also from the perspective of other key individuals intertwined within this experience, a case study was the most appropriate way by which to ensure an understanding of these experiences and associated multiple realities. Furthermore, I considered the case study approach to be the most appropriate as it paid homage to not only the adopted constructivist-interpretive positioning, but also the desire to explore transition from multiple perspectives.

The decision to focus on young people who are survivors of childhood cancer in this study was borne both from the experiences of the young people I engaged with in an advisory capacity and from the clinical directive of long-term follow-up care, as best practice ethos dictates that all survivors of childhood cancer should be followed up for

life (Scottish Intercollegiate Guidelines Network, 2004). Indeed, the recent Scottish Government Cancer Plan for Children and Young People 2012-2015 (The Scottish Government, 2012) has committed to the development and provision of cancer services that are appropriate to the needs of teenagers and young adults up to the age of 25. This policy document adopts the encompassing term 'young people' to define the population to which it refers. This thesis therefore mirrors these developments by adopting the term 'young people' when discussing participants in this study. Despite on-going developments, it is, however, recognised that the provision of this long-term follow-up care can be challenging, particularly when survivors of childhood cancer reach adolescence and young adulthood – characteristics of these developmental milestones advocate for a planned transition of the provision of care from the paediatric to the adult setting (Freyer *et al.,* 2006). Yet, poor or bad transition can result in a number of negative effects for young people, including gaps in medical supervision and stressful experiences for the young person (Viner, 2003).

However, it was further identified that transition is experienced by other key individuals within the context of the young person's childhood cancer experience, namely friends or family members and health care professionals. The wider reaching influence of this transition was considered to be particularly apparent and relevant within the context of previous understandings of parental roles in paediatric oncology care (McKenna *et al.*, 2010) and young people's and families' relationships with their paediatric oncology team (Harrington *et al.*, 2009). However, further informed by the young people I spoke to in an advisory capacity, it was acknowledged that the specificities of just who these individuals are, from either group, may vary from young person to young person. Thus, to ensure this study captured the experiences of the individuals whom young people regarded as the most important within the context of their experience, each young person was asked to self-nominate both a friend or family member and a health care professional to also participate in an interview. These interviews, as with the examination of young people's case notes, permitted the consideration of the multiple perspectives of the experiences within, and indeed between, cases. Such exploratory methods permitted an in-depth and detailed understanding of the transition experience for survivors of childhood cancer to be

generated. This approach, it will be revealed in this thesis, has provided an important understanding of the experience of transition, thereby adding a valuable contribution to knowledge in this field.

Having outlined the rationale for this thesis, section 1.2 shall now briefly outline the structure of this thesis.

1.2 Structure of the thesis

The next two chapters (Chapters 2 and 3) of this thesis review relevant literature. The first literature review chapter, Chapter 2, focuses on childhood cancer, with an overview of incidence, mortality and, importantly in the context of this thesis, survivorship. Chapter 2 also provides some background on different childhood cancer diagnoses in addition to introducing the concepts of long-term follow-up and long-term late effects. Discussion in Chapter 2 provides a suitable framework for Chapter 3, in which transition is discussed. Chapter 3 outlines definitions of transition and considers the existing body of evidence. Chapter 3 further considers the importance of understanding patient experience, and particularly considers the ways in which patient experience has informed the transition evidence base thus far.

In Chapter 4, the adopted philosophical positioning is outlined, allowing for consideration and rejection of particular strategies of inquiry, prior to outlining the rationale for the adoption of a case study approach in this study. This chapter also considers different approaches to case study research, prior to identifying the approach adopted in this study.

In Chapter 5, the actual methods adopted in this study and the conduct of the current study is outlined. The approaches to analysis adopted in this study are also outlined in Chapter 5.

In Chapters 6 and 7, the results from this study are presented. Chapter 6 introduces the study sample and provides an overview of the interviews conducted in this study,

before a discussion of the orienting construct identified in this study: 'The experience of readiness in the context of transition'. The three main supporting themes of this orienting construct are also introduced in Chapter 6, namely, 'The experience of childhood cancer', 'Planning and preparation: transition or transfer?', and 'A process of change'. Discussion in Chapter 6 provides the framework for Chapter 7, in which the three main themes and the supporting sub-themes identified in this study are presented along with the study findings.

Finally, in Chapter 8, the findings from this study in relation to the wider literature are discussed, as are the strengths and weaknesses of the strategy of inquiry adopted. Chapter 8 closes with an overview of the implications of this study for future research and a series of recommendations for clinical practice, borne from this study's findings.

Chapter 2 Childhood Cancer

2.1 Introduction

Childhood cancer is a term which encompasses the variety of malignancies diagnosed in children. This chapter presents a brief overview of the clinical context of childhood cancer by considering incidence rates, diagnostic groups, treatment modalities and rates of survivorship. Also discussed within this chapter are long-term follow-up (LTFU) care arrangements, long-term late effects and paediatric oncology care. The implications of such issues within a survivorship and, consequently, transitional care context, are also considered.

2.2 Incidence of childhood cancer

In the UK alone, around 1,500 new cases of childhood cancer are diagnosed per annum (Cancer Research UK, 2010b), with approximately 120 new diagnoses each year in Scotland (Information Statistics Division, 2009). In the UK, the risk of being diagnosed with cancer by the age of 14 is approximately 1 in 500 (Cancer Research UK, 2010a). In terms of age at diagnosis, within Scotland, approximately 56 cases per year are diagnosed in the youngest age group, that of 0 – 4 years, accounting for 46% of all childhood cancers in Scotland. The next quintile, ages 5 – 9 years, accounts for approximately 26% of all childhood cancers, whilst ages 10 – 14 years account for 28% of all cases (Information Statistics Division, 2009). Globally, it is estimated that 1 in every 450 children will develop cancer by the time they reach adulthood (Izraeli and Rechavi, 2004). Despite considerable advances in successful treatment regimes, childhood cancer is, within a global context, the leading cause of death in children after the neonatal period (Izraeli and Rechavi, 2004; Brown, 2006).

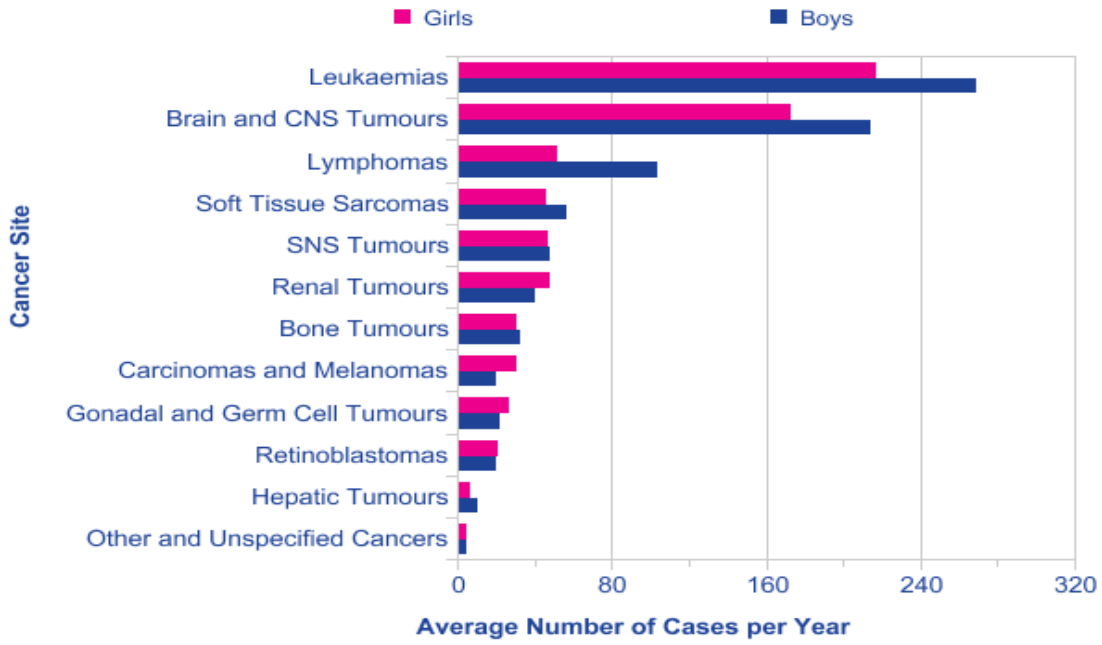
2.3 Childhood cancer diagnoses

Childhood cancers vary greater than adult cancers, both in terms of anatomical site and histological type (Izraeli and Rechavi, 2004; Scottish Intercollegiate Guidelines Network, 2004), and those tumours commonly diagnosed in adults, such as breast,

lung and large bowel, are rarely found in children. In a similar vein, those cancers which occur in childhood are rarely diagnosed in adults (Cancer Research UK, 2010b). Many childhood cancers are often not amenable to early diagnosis, often do not obviously present as pre-malignant lesions, and are rarely preventable (Izraeli and Rechavi, 2004).

The three most common diagnoses of cancer in children are leukaemias, brain and central nervous system tumours, and lymphomas, which, in total, account for around 66% of all cancers diagnosed in those aged 0 - 14 years old (Cancer Research UK, 2011). The most common leukaemia diagnosis in children, and indeed the most common diagnosis of all the childhood cancers, is Acute Lymphoblastic Leukaemia (ALL), as this accounts for around a quarter of all childhood cancers in the UK (Cancer Research UK, 2011). ALL is "a malignant disorder of lymphoid cells found in the bone marrow that migrates to virtually every organ system, including the central nervous system (CNS), via the circulatory system" (Mulhern and Butler, 2006, p.263) and it can occur at any age, although the peak years of incidence are between 3 – 6 years old (Brown, 2006). The next most common diagnosis, brain and CNS tumours, account for around a quarter of all diagnoses of cancer in children in the UK, whereas lymphomas are the third most common type of diagnosis and they account for around a tenth of all diagnoses of cancer in children (Cancer Research UK, 2011). In terms of gender, some similarities are evident in regards to the most common diagnoses, as in girls, leukaemia and CNS tumours are particularly prevalent, accounting for 34% and 24% of diagnoses respectively. Likewise, in boys, leukaemia accounts for 34% of diagnoses, with a further 21% attributable to CNS tumours (Campbell *et al.*, 2004). Other common malignancies which may present during childhood, including soft tissue sarcomas, such as rhabdomyosarcomas, bone sarcomas such as osteosarcoma and embroyonal tumours such as retinoblastomas (Brown, 2006; Cancer Research UK, 2011), are summarised in a UK context by gender in Figure 1.

Figure 1: All childhood cancers, average numbers of new cases, children (0-14), Great Britain, 2001-2005



Source: Cancer Research UK (2011)

2.4 Aetiology of childhood cancers

Childhood cancers are characteristically different to adult cancers, as childhood cancers typically arise in those tissue or organ areas that develop most rapidly during the neonatal period (Izraeli and Rechavi, 2004). Aetiologically, little is known about childhood cancers (Brown, 2006), as the factors involved in the causes of these malignancies are unclear (Tomlinson, 2005). Most cancers in childhood cannot, unlike cancers encountered in adulthood, be prevented and are often not amenable to early diagnosis (Izraeli and Rechavi, 2004). The causes of childhood cancer are considered by some to occur in utero, whereas with adult cancers, various environmental or lifestyle factors are often attributed as aetiological factors in many of these diagnoses (Izraeli and Rechavi, 2004; Brown, 2006). Because of this lack of knowledge, establishing risk factors for specific forms of childhood cancer is of considerable interest, with various risk factors, including parental age and maternal use of antibiotics, now being considered in case-control studies (Johnson *et al.*, 2009; Kaatsch

et al., 2010). Rarely, however, are consistently established aetiologic factors actually known (Brown *et al.*, 2007). In spite of this lack of evidence, a number of potential hypotheses surrounding possible causes of childhood cancers have been postulated in recent review papers, including exposures to environmental toxins (household chemicals, pesticides or solvents) at foetal, parental or early childhood stages; paternal pre-conception occupational exposure to radiation or smoking; medical conditions prior to conception or during pregnancy; or maternal exposure to medications such as oral contraceptives or fertility drugs (Linet *et al.*, 2003; Wild and Kleinjans, 2003; Stiller, 2004; Anderson, 2006). Evidence from such studies, nonetheless, is often limited by the approaches adopted, particularly as many studies that have examined potential associations between environmental factors with childhood cancer have frequently adopted retrospective case-controlled approaches and have often included samples with both variations in diagnoses and variations in timings of exposure to the suspected risk factors (Brown *et al.*, 2007).

2.5 Treatments for childhood cancers

The organisation and delivery of treatments for childhood cancer has developed somewhat over recent decades. The United Kingdom Children's Cancer Study Group (UKCCSG) was established in 1977 as a national organisation for paediatric oncologists, clinicians and scientists with a particular interest in paediatric oncology[1] (Children's Cancer and Leukaemia Group, 2006-2012a). Today, 21 UKCCSG centres around the UK are responsible for the care of almost all children diagnosed with cancer (Children's Cancer and Leukaemia Group, 2006-2012b) and for co-ordinating clinical trials for treatments for many childhood cancers. Indeed, protocols offered at large paediatric hospitals allow patients to be treated in controlled circumstances and allow for data to be collected on an ongoing basis (Nelson and Meeske, 2005). The advantages of treating children with standardised treatment protocols and at specialised centres

[1] The UKCCSG and the UK Childhood Leukaemia Working Party (UK CWLP) merged in August 2006 to form The Children's Cancer and Leukaemia Group (Children's Cancer and Leukaemia Group, 2006-2012a).

have been consistently reported in recent decades (Stiller and Draper, 1989; Marina *et al.*, 1992; Hudson *et al.*, 2012).

For children diagnosed with cancer, four primary treatment modalities are available, and may be administered individually or via various multi-modal combinations: chemotherapy, radiation therapy, surgery, and bone marrow transplantation (Brown, 2006). There is some suggestion that growing children are able to tolerate the acute side effects associated with such treatments relatively well in comparison to adults (Izraeli and Rechavi, 2004; Bhatia *et al.*, 2007), but studies which have considered patient and parent experiences of childhood cancer and treatments would contest this somewhat medically-orientated view. For example, not only do patient and parent perspectives indicate that the impact of acute side effects is a particularly significant aspect of children and their parents' experiences of childhood cancer (Soanes *et al.*, 2009), they also suggest that the meanings these individuals assign to the symptoms experienced are multiple and continuous (Woodgate *et al.*, 2003). So, whilst treatment toxicities may be closely monitored (Alcoser and Rodgers, 2003), the range of acute side effects of treatment that children can experience are vast, and may include: immunosuppression and infection, thrombocytopenia, malnutrition, anaemia, mucositis, pain, and nausea and vomiting (Bryant, 2003). Indeed, the physical impact of side effects such as these has recently been discussed by both children with brain tumours and their parents, with the impact of these notable within the context of their wider cancer experience (Soanes *et al.*, 2009).

In terms of the various treatment modalities, chemotherapy, that which uses chemical substances in drug form, is considered to be the primary treatment modality used to treat many paediatric cancers (Alcoser and Rodgers, 2003; Brown, 2006; Ronghe and Murphy, 2008). The chemotherapeutic agents prevent rapidly growing cancer cells by means of oral administration, or by injections, either subcutaneous or intramuscular, or intravenous or intrathecal methods of administration (Alcoser and Rodgers, 2003; Brown, 2006). Anticancer drugs tend to be cytotoxic, which means as cell poisons, the drugs act on most cells; not only are the malignant cells targeted, but so too are the healthy ones (Ronghe and Murphy, 2008). However, as both healthy and malignant

cells are destroyed during chemotherapy treatment, children who receive this treatment modality are likely to experience a range of side-effects, including nausea, vomiting, low blood counts that make them susceptible to infection, loss of appetite, hair loss, or fatigue (Brown, 2006).

Radiation therapy is also often used to treat children with cancer, although the use and role of this treatment modality has decreased and changed somewhat in recent decades with the advent of more effective chemotherapy treatment regimes, increasing recognition of the long-term late effects of radiotherapy treatment and improvements in terms of staging and surgical procedures (O'Brien and Tomlinson, 2005; Cowie, 2008). The use of radiation therapy, does, however, vary depending upon the child or young person's diagnosis (Cowie, 2008). For example, radiation therapy is now almost entirely omitted in the treatment of diagnoses such as non-Hodgkin's lymphoma, where it tends only to be used in the event of palliation, relapse or CNS disease (Cowie, 2008), compared to brain tumours, where it continues to be used more as a primary or adjuvant treatment modality (Shih *et al.*, 2009).

Like chemotherapy, radiation therapy too has a number of associated general acute side effects that children may experience during treatment, including fatigue, irritation of the skin at the radiation site, and loss of appetite, nausea and vomiting, and hair loss in the field of radiation (Alcoser and Rodgers, 2003; Brown, 2006; Cowie, 2008). Side effects of radiation therapy are, however, not limited to the acute phase of treatment, as there are a number of late effects of radiation therapy which typically become apparent six to twelve months following treatment completion (Alcoser and Rodgers, 2003) and are irreversible (O'Brien and Tomlinson, 2005). The extent and severity of radiation therapy-associated late effects can vary (Cowie, 2008), with any impairments to organ functioning following radiation dependent upon the type of organ involved (Cowie, 2008). Further, radiation to the brain can increase the risk of neurocognitive impairments (Shih *et al.*, 2009), with a decrease in white matter in the brain, leading to potential significant learning impairments (Mulhern and Butler, 2006). There are further risks of hypothyroidism, an abnormality of the thyroid gland, should cranial radiation therapy be received (Shih *et al.*, 2009), as well as pituitary gland dysfunction

and pulmonary fibrosis or cardiac problems as a result of both dose-related and site-related radiation therapy delivery (Shih *et al.*, 2009; Armstrong *et al.*, 2010).

It is also possible that children will undergo surgery to remove their tumour (O'Neill, 2005). Previously, surgery tended to be the principle treatment modality for solid childhood cancer tumours, but now, following the introduction of chemotherapy and radiation therapy, a multi-modal approach to treatment, which combines surgery, chemotherapy and radiation therapy, is more commonly employed (Alcoser and Rodgers, 2003). Such a multifaceted approach is considered to have led to considerable improvements in survival rates of children diagnosed with cancer (O'Neill, 2005), meaning the surgical team have become integral members of the patient's medical team (Alcoser and Rodgers, 2003). A variety of surgical interventions and techniques to manage childhood cancer malignancies exist (O'Neill, 2005), but despite advances, as with chemotherapy and radiation treatments, surgical management of children with solid tumours, too, presents a number of risks, complications and possible long-term effects, particularly as there is potential injury to major vessels, thus consequent extended resections (O'Neill, 2005) and surgical-associated complications, including bleeding and infection (Alcoser and Rodgers, 2003).

Lastly, bone marrow transplantations, or hematopoietic stem cell transplant (HCST) treatment (Alcoser and Rodgers, 2003), involves a transplantation of the marrow of the bone or cells which produce blood-forming tissues, and has increased in use in the treatment of children with cancer over recent years (Brown, 2006). Patients who receive a bone marrow transplant have usually received a combination of chemotherapy and radiation therapy previously, resulting in a decrease of the bone marrow functioning. This allows new bone marrow to be administered to the patient intravenously (Brown, 2006). However, during the course of a bone marrow transplantation, a patient is at significant risk of infection, thus must remain in isolation to prevent any infection (Brown, 2006). Again, there are a number of potential long-term complications and side-effects associated with a bone marrow transplantation, including pulmonary fibrosis, cardiomyopathy, renal toxicity or failure,

dysfunctions with thyroid or growth, or gonadal failure or amenorrhea (Alcoser and Rodgers, 2003).

Although a range of treatments are available to children diagnosed with cancer, courses of treatment and their associated duration are diagnostically variable. First of all, children diagnosed with the most common type of childhood cancer, ALL, usually require an extended treatment period, typically between two to three years in duration (Tomlinson, 2005), as protocols to treat ALL are typically split into four distinct treatment phases: remission induction, intensification/consolidation, CNS-directed therapy and maintenance/continuing treatment (Westlake and Bertolone, 2002; Tomlinson, 2005). Maintenance therapy is often required for a prolonged period due to the presence of undetectable, but potentially fatal, levels of leukaemia (Mulhern and Butler, 2006). Furthermore, there is some potential for a child diagnosed with ALL to relapse following initial treatment completion, as approximately 20% of these children will do so within the first year following completion of treatment, with a remaining risk of 2%-3% per year for the following 3-4 years (Mulhern and Butler, 2006). Often, combination chemotherapy is delivered to children diagnosed with ALL, whilst cranial irradiation may be given to those who experience a CNS relapse (Mulhern and Butler, 2006).

Alternatively, for children diagnosed with the second most common cancer diagnosis in childhood, brain and CNS tumours, surgical resection of the tumour will usually be undertaken, as will chemotherapy, either with or without cranial or craniospinal irradiation (Mulhern and Butler, 2006; Packer, 2008). For children with brain tumours, and indeed other paediatric oncology and haematology diagnoses, there is widespread agreement that the best practice for treatment, with the aim of improving survival, is one that incorporates a broad multi-disciplinary team (Fitzmaurice and Beardsmore, 2005; Spinetta *et al.*, 2006; Rechnitzer, 2011). For children diagnosed with brain tumours, the length of treatment period depends on the multi-modal combination of treatment delivered, as cranial irradiation alone can typically be delivered once a day, five days per week, for a period of up to six weeks. Currently, surgery, chemotherapy

and radiation therapy are the mainstay treatment modalities for the majority of brain tumours (Partap and Fisher, 2007).

2.6 Childhood Cancer Survivorship

A child or young person is often considered to be 'cured' from childhood cancer if they have had a five-year disease-free remission period (Bradwell and Hawkins, 2000). However, 'cure' may not be achieved in the holistic sense, as it is now commonly regarded that there is a need "to look beyond the absence of disease" (Bradwell and Hawkins, 2000, p.312), particularly in the context of late effects associated with the childhood cancer experience. This means the five-year disease-free remission period has proved particularly important in providing focus for the British Childhood Cancer Survivor Study (BCCSS) (University of Birmingham, 2012b) and the US-based Childhood Cancer Survivor Study (CCSS) (St Jude Children's Research Hospital, 2012a) programmes of work, in which the long-term experiences of large cohorts of five-year survivors have been characterised (American Academy of Pediatrics, 2009). However, shifts in the conceptualisation of survivorship mean that many now regard issues around survivorship from the point of the child's diagnosis and beyond (Bradwell and Hawkins, 2000). In many ways, this perception is consistent with recent interpretations of the term 'cancer survivor', where there is some agreement that a cancer survivor is someone living with cancer as well as someone who has survived beyond the treatment for, or presence of, cancer, for five years and longer (Corner and Richardson, 2007; Macmillan Cancer Support, 2008; The Scottish Government, 2008a). Indeed, Macmillan Cancer Support consider that a cancer survivor is "someone who has completed initial cancer management and has no apparent evidence of active disease, or is living with progressive disease and may be receiving cancer treatment but is not in the terminal phase of illness (last six months of life), or has had cancer in the past" (Macmillan Cancer Support, 2008, p.6). The foundations of this definition are particularly relevant within the context of childhood cancer, particularly as improvements in treatments have resulted in increasing numbers of young people now surviving the illness, meaning increasing numbers of this population are now considered to have had the illness in the past (Aziz *et al.*, 2006). These young people

may, as a consequence, be living with long-term consequences of treatments for this illness (Shih *et al.*, 2009; Armstrong *et al.*, 2010), yet this element of the illness experience is less explicit in the definition of survivorship posited by Macmillan Cancer Support (2008), meaning it is with some hesitance that parallels are drawn between the experience of survivorship for people diagnosed with cancer in childhood and that of those diagnosed in adulthood. It is only relatively recently that comparable debates have emerged in an adult context, with calls for the experience of cancer in adulthood to be considered a chronic illness (Cayless *et al.*, 2010; Hubbard *et al.*, 2010; McCann *et al.*, 2010).

Childhood cancer survivorship developments are particularly evident when relevant epidemiological data are considered. For example, improvements in treatments mean that, compared to the late 1960s, when just 28% (equivalent to three in ten) of children diagnosed with cancer survived for five years or more, approximately eight in ten (78%) children now survive for five years beyond diagnosis in the UK (Cancer Research UK, 2010c). Within a Scottish context, similarly notable positive survival rates have been observed: one-year survival figures have increased from 74% for the period 1975-1979 to 89% in the period 1995-1999 (Campbell *et al.*, 2004). Five-year survival figures have also increased, with a rise from 50% in 1975-1979 to 76% for the 1995-1999 period in Scotland (Campbell *et al.*, 2004). Today, it has been suggested that there are over 7,000 children and young adults living in Scotland aged under 24 years who have had a diagnosis of cancer, with approximately 6,000 of these having been diagnosed more than five years ago (The Scottish Government, 2012). Survival rates are predicted to continue to increase, with future projections suggesting that the population of young adult cancer survivors will be around 11,000 by the year 2030, therefore constituting 1 in 100 of the young adult population (Campbell *et al.*, 2004).

Indeed, high survivorship rates are the ultimate *sine qua non* in paediatric oncology, as is evident in recent reports which suggest that nearly 80% of patients diagnosed with cancer in childhood are achieving cure thanks to advancing and improving treatments now available (Freyer and Kibrick-Lazear, 2006). However, cure from cancer is not guaranteed (Aslett *et al.*, 2007) and some variability in terms of survivorship is evident.

This variability is often attributable to a number of dependent factors, such as diagnosis, demographic characteristics (age, sex and race), and clinical characteristics at the time of presentation (location and stage of disease) (Robinson *et al.*, 2009). Nonetheless, successful outcomes for long-term survivors of childhood cancer are largely dependent on the diagnosis and treatment therapies received (Mahajan and Jenney, 2004).

It is possible, though, that the therapies children and young people receive to treat their cancer result in consequential long-term morbidities or long-term late effects (Scottish Intercollegiate Guidelines Network, 2004). Studying the long-term consequences and outcomes as a result of treatments responsible for the increases in survival has therefore been recognised as a priority (Leisenring *et al.*, 2009; Robison *et al.*, 2009). Indeed, issues surrounding survivorship have received increasing attention across the literature in recent years, particularly as the importance of exploring and understanding the consequences of childhood cancer diagnoses and associated treatments on the lives of young adult survivors of childhood cancer have emerged as priority issues within this context (Stam *et al.*, 2005; Jörngården *et al.*, 2006; Sundberg *et al.*, 2009; Harila *et al.*, 2010; Sundberg *et al.*, 2010; Wakefield *et al.*, 2010; Sundberg *et al.*, 2011a; Sundberg *et al.*, 2011b).

To aid the study of these long-term consequences and outcomes of survivorship of childhood cancer, specific care arrangements are commonly in place in the clinical setting. Within this context, long-term late effects and long-term follow-up service provision are commonly discussed in tandem. Thus, forthcoming sections 2.6.2 – 2.6.2.2 will continue this discussion, by introducing the concept of long-term follow-up, prior to providing an overview of the long-term late effects which survivors of childhood cancer may experience and the potential impact of these.

2.6.2 Long-Term Follow-Up

Increasing numbers of teenagers, young, and middle-aged adults are now considered to be survivors of childhood cancer (Nelson and Meeske, 2005; Robinson *et al.*, 2009),

with an exponential increase in this population over recent years (Hudson *et al.*, 2012). Successful therapy can be associated with a range of potential long-term physical and psychosocial sequelae (Mahajan and Jenney, 2004) and survivors of childhood cancer are at an increased risk of morbidity due to treatment-related adverse effects (Blaauwbroek *et al.*, 2007). Commonly, potential physical and psychosocial sequelae are referred to as long-term late effects and are defined as:

> *The physical, psychological, social and/or economic chronic or late occurring consequences of cancer treatment persisting or occurring at least 5 years from diagnosis.* (Levitt and Eshelman, 2008, p.169)

Despite this definition, initially, knowledge and understanding surrounding long-term late effects such as those aforementioned was somewhat limited (Oeffinger *et al.*, 2000). More recently, though, thanks to an expansive body of publications in which survivors of childhood cancer have been identified as being at increased risk of late health problems as a consequence of their childhood cancer experience (Freyer, 2011), our understanding of this population and these needs have increased. Certainly, the expansive programmes of work conducted by the CCSS in the USA and Canada and the BCCSS introduced previously in section 2.6 have been instrumental in adding to this empirical base, with over 170 and 107 articles as of April 2012 published by these groups respectively since the late 1980s (St Jude Children's Research Hospital, 2012b; University of Birmingham, 2012a).

The risk of developing late effects such as those defined by Levitt and Eshelman (2008) increases over time, thus life-long follow-up is recommended to allow the periodical study of this population and to allow early detection and intervention for potentially serious late-onset complications of therapy-related sequelae (Oeffinger *et al.*, 2000; Aslett *et al.*, 2007; American Academy of Pediatrics, 2009). To do so, clinicians advocate for the provision of long-term follow-up (LTFU) as an essential element of the care provided to children and young adults treated for cancer (Skinner *et al.*, 2007).

The principle of LTFU is to provide optimal care to people who are survivors of childhood cancer (Friedman *et al.*, 2006). The specific purposes of this care do, nonetheless, vary depending upon young people's post-treatment staging. Initially, the purpose of LTFU is to allow the screening, detection and surveillance of late effects, thereby permitting the treatment of any disease recurrence promptly and improving outcomes and quality of life (Oeffinger, 2004; Aslett *et al.*, 2007). Emphasis shifts laterally to the identification and anticipation of any late effects of treatment therapies (Aslett *et al.*, 2007), particularly as the impact of chemotherapy and radiation treatments on the ageing process of normal tissues and the consequential impact on the development of other common age-related adult health problems are largely unknown (Oeffinger, 2004).

Clinical arrangements for the provision of LTFU over recent years have been the result of the development and implementation of long-term follow-up guidelines. In the USA, the Children's Oncology Group (COG) developed exposure-based health screening guidelines, to help facilitate the systematic and comprehensive follow-up of survivors of childhood cancer (American Academy of Pediatrics, 2009). These guidelines have been designed to raise awareness of the risks of long-term treatment-related late effects in adult survivors of childhood cancer, to allow early identification and early intervention of these sequelae (American Academy of Pediatrics, 2009). In the UK, similar progress is identifiable, with the development of a Therapy Based Long Term Follow Up Practice Statement (Skinner *et al.*, 2005) and Scottish Intercollegiate Guidelines Network (SIGN) Guidelines (Scottish Intercollegiate Guidelines Network, 2004). The purpose of the Practice Statement, like the COG Guidelines, is to "inform and guide all clinicians responsible for the clinical follow up of long term survivors of treatment for childhood malignancy, including survivors of bone marrow transplantation (BMT)" (Skinner *et al.*, 2005, p.3). The SIGN guideline *Long term follow-up of survivors of cancer in children and young people* (Scottish Intercollegiate Guidelines Network, 2004) produced a systematic review of evidence on which scientifically sound recommendations for monitoring and follow-up are based. A number of key areas are covered by this SIGN guideline, including: assessment and achievement of normal growth; assessment of thyroid function; achievement of

normal progression through puberty and factors which affect fertility; early identification, assessment and treatment of cardiac abnormalities; and the assessment and achievement of optimal neurological development and psychological health (Kelnar and Wallace, 2004; Scottish Intercollegiate Guidelines Network, 2004). Guidelines such as those developed by the COG and SIGN prioritise standardisation of care for survivors of childhood cancer, and advocate the need for patients and others of importance within the context of their health care experience, to be provided with written summaries of the diagnosis, treatments received and a list of signs of late effects (Scottish Intercollegiate Guidelines Network, 2004; American Academy of Pediatrics, 2009). Such information, SIGN (2004) state, is important from a patient information perspective, particularly so because it should reflect the particular stage of the young person's illness experience. In addition, recognising that a number of factors will dictate the degree and nature of long-term morbidity risk (Scottish Intercollegiate Guidelines Network, 2004), SIGN proposed three levels of follow-up, as summarised in Table 1. Lately, questions have surrounded the feasibility and benefit of providing life-time LTFU for all survivors of childhood cancer (Aslett *et al.*, 2007), with a recent systematic literature review which aimed to review models of care for follow-up of survivors of childhood cancer indicating this may be neither feasible nor beneficial for all individuals (Heirs *et al.*, 2010).

Table 1: Possible levels of follow-up for patients five or more years from completion of treatment

Level	Treatment	Method of follow-up	Frequency	Examples of tumours
1	Surgery alone Low-risk chemotherapy	Postal or telephone	1-2 years	Wilms' Stage I or II Langerhans cell histiocytosis (single system disease) Germ cell tumours (surgery only)
2	Chemotherapy Low-dose cranial irradiation (≤24 Gy)	Nurse or primary care-led*	1-2 years	Majority of patients (e.g. ALL in first remission)
3	Radiotherapy, except low-dose cranial irradiation Megatherapy	Medically supervised long- term late effects clinic	Annual	Brain tumours Post bone marrow transplantation Stage 4 patients (any tumour type)

* with appropriate training protocols

ALL: Acute Lymphoblastic Leukaemia; BMT: bone marrow transplantation

Reproduced from Scottish Intercollegiate Guidelines Network (2004, p.5)

Regardless of current debates, the provision of appropriate LTFU for survivors of childhood cancer is an issue which has been of interest within the literature for many years. For example, in the USA, Oeffinger and colleagues (1998) explored the ways in which members of the Children's Cancer Group (CCG) and the Pediatric Oncology Group (POG) provided follow-up care to young adult survivors of childhood cancer in the late 1990s, with Aziz *et al.* (2006) conducting a similar exploration, also in the USA, some years later. Oeffinger *et al.* (1998) found that in over 90% of the programmes surveyed, adult survivors of childhood cancer were being followed-up by a paediatric haematologist-oncologist in a paediatric institution, with 93% of the programmes having a paediatric oncologist as the physician in charge. Similar levels of paediatric leadership were revealed by Aziz *et al.* (2006) in their study; 83% of the directors of the LTFU programmes surveyed were also paediatric oncologists. Although disparate in

their samples (182 versus 24 respectively), highlighting these two studies serves a dual purpose. Firstly, the prominence of paediatric oncologists in the provision of LTFU for young adult survivors of childhood cancer appears to reign supreme; more of the programmes surveyed by Aziz *et al.* (2006) were directed solely by paediatric oncologists than other specialists. Against an evolving policy backdrop for the provision of age-appropriate care, it could be argued that notable advancements may have been made in terms of this care provision in the intervening years following the Oeffinger *et al.* study (1998). Secondly, common to both studies, although the issue of LTFU and its appropriate provision is very much patient-centred, neither study sought to explore the experiences of young people in relation to their LTFU care experiences, thus opting to focus primarily on service-orientated issues. An experiential paucity such as this was also demonstrated in a review of psychosocial service provision in the UK (Mitchell *et al.*, 2005).

Without doubt, the paucity of patient and family perspective and experiential data in relation to LTFU care is striking. For the most part, literature in this field focuses on clinical perspectives of the provision of LTFU care; surveys of current clinical practice to help determine future service provision are often conducted and reported (Oeffinger *et al.*, 1998; Aziz *et al.*, 2006; Greenfield *et al.*, 2009; Ristovski-Slijepcevic *et al.*, 2009; Henderson *et al.*, 2010b). Whilst the intention is not to disregard the importance of such studies, a significant gap in this literature is highlighted, notably that of patient experiences of LTFU care.

Indeed, the lack of patient perspectives and experiences in the context of LTFU care provision in the literature was previously identified by Aslett *et al.* (2007) in their review which sought to synthesise evidence on LTFU care from three sources: empirical research, commentary papers and guidelines. However, within the empirical research reviewed, Aslett *et al.* (2007) identified only five papers which considered the views of adult survivors of childhood cancer in the provision of LTFU care from their perspective. Even more striking within this small collection of papers was the extent to which the individual experiences of survivors of childhood cancer were not explored within this context; none of these papers conducted in-depth interviews with

participants. Rather, questionnaires, the Delphi method and focus groups were the methodological approaches of choice (Aslett *et al.* 2007).

Yet, in one of the few studies which has prioritised experiences, Arvidson *et al*. (2006) previously explored how the health care needs of survivors of childhood cancer were met. In their sample of 245 Swedish young adult survivors of childhood cancer, just over 60% reported they were satisfied with their experience of follow-up. However, only 40% of the sampled population reported having regular, scheduled follow-up appointments (Arvidson *et al.*, 2006). As with the Oeffinger *et al.* (1998) and Aziz *et al*. (2006) studies, Arvidson *et al.* (2006) found the input of the paediatric oncologists to be particularly prevalent – 36% of the young adult survivors of childhood cancer receiving LTFU appointments were being seen by paediatric oncologists, despite 19 of 35 of the individuals being 20 years or older (Arvidson *et al.*, 2006).

The importance of the provision of LTFU was further explored from a patient health perspective by Blaauwbroek *et al.* (2007). Inverting the issue, however, the authors recruited survivors of childhood cancer not involved in regular LTFU, to allow their health status and health-related quality of life to be assessed. One-hundred-and-twenty-three participants were recruited, aged between 0 - 20 years at the time of diagnosis, and who were now 9 - 38 years from the point of diagnosis. Using the Common Terminology Criteria for Adverse Events, Version 3 (National Cancer Institute, 2006) to grade late effects, they found 54% of their sample had a mild grade late effect, 39% had a moderate to severe grade late effect and 70% had two or more late effects (Blaauwbroek *et al.*, 2007). Importantly, this survey highlighted that 33% of these patients were diagnosed with a late effect graded between 2-4 that was previously unknown to them and for which treatment or closer surveillance was required (Blaauwbroek *et al.*, 2007). Whilst this study did not include a control group to permit comparisons, the results are indicative of two important issues. Firstly, the provision of LTFU by clinicians with knowledge of late effects is important for the health and well-being for adult survivors of childhood cancer, as is, secondly, the knowledge and education of patients of the late effects they may experience

(Blaauwbroek *et al.*, 2007). Thus, this study highlighted the importance of active monitoring of this nature, from both patients' and clinicians' perspectives.

The provision of LTFU is important for three broad reasons. First, information on long-term effects of treatment can help inform the development of treatment protocols and ongoing follow-up for survivors of childhood cancer, as this care facilitates the monitoring and increases our understandings of the potential treatment-related sequelae survivors of childhood cancer may experience. Furthermore, organised and specific care provision, such as that afforded by LTFU, allows such sequelae to be assessed and detected appropriately (Klosky *et al.*, 2008), particularly given late effects can emerge long after treatment completion (Eiser *et al.*, 2007; Absolom *et al.*, 2009). Second, LTFU can optimise care for the young person and their family (Eiser *et al.*, 2007). Finally, structured monitoring via LTFU is vital, particularly so in light of reports that indicate approximately one-third of survivors of childhood cancer will have a serious or life-threatening late effect as a result of the treatments they received for their cancer diagnosis (Oeffinger and Hudson, 2004). These long-term late effects are often regarded as either physical or psychosocial in nature and are discussed in turn in sections 2.6.2.1 and 2.6.2.2 that follow.

2.6.2.1 Physical late effects

Growing children are at risk of various deleterious late effects of cancer treatments. Almost every organ system in the body can be affected by the treatments required to cure cancer in childhood (American Academy of Pediatrics, 2009). Heart, lungs and kidneys can all be affected by the chemotherapy, radiotherapy and/or surgery required to treat and cure paediatric malignancies (American Academy of Pediatrics, 2009) and survivors of childhood cancer are at risk of common adulthood diseases impacting significantly on organs treated during their childhood illness (Ginsberg *et al.*, 2006). Further, such individuals may be at risk of second malignancies, neurocognitive deficits and infertility, or have problems with their growth and development (Izraeli and Rechavi, 2004; Jones, 2008; Levitt and Eshelman, 2008; American Academy of Pediatrics, 2009).

Our understanding surrounding the physical consequences and long-term late effects of cancer in childhood and its associated treatments has grown considerably in recent years. This increased understanding is, in many ways, attributable to studies such as the BCCSS and CCSS. The multi-institutional CCSS study, for example, which is composed of over 14,000 individuals who survived for five years or more following diagnosis of cancer in childhood or adolescence and 4,000 siblings who provide the comparison group for the study (Leisenring *et al.*, 2009), has allowed the long-term late effect experiences of participants to be characterised. Similarly, the BCCSS is the first national population-based study undertaken in Britain of survivors of childhood cancer to assess a variety of possible adverse health outcomes of both childhood cancer and its associated treatments, in the underlying cohort of over 17,000 individuals diagnosed between 1940 and 1991 and who had survived for at least five years following diagnosis (University of Birmingham, 2012b).

Studies of this scale and duration are important in the context of increasing knowledge of the impact of long-term late effects on the lives of survivors of childhood cancer and, as a result, publications from these large-scale, multi-institutional studies amass into the hundreds. Extensive findings have been explored thus far within the various CCSS- and BCSS-associated publications, including incidence and risks of cardiac complications, such as congestive heart failure, myocardial infarction and pericardial disease in adult survivors of childhood and adolescent cancer (Mulrooney *et al.*, 2009; Tukenova *et al.*, 2010); various ocular deficits, including blindness, cataracts or glaucoma (Whelan *et al.*, 2010); risks of subsequent malignancies in survivors of childhood cancer (Rubino *et al.*, 2003; Guibout *et al.*, 2005; Davies, 2007; Taylor *et al.*, 2009); the medical care of long-term survivors (Nathan *et al.*, 2008); the knowledge survivors of childhood cancer have about their past diagnosis and treatments (Kadan-Lottick *et al.*, 2002); fertility-associated issues (Green *et al.*, 2009a; Green *et al.*, 2009b; Reulen *et al.*, 2009; Green *et al.*, 2011); and abnormalities with endocrine systems (Gurney *et al.*, 2003) to name but a few.

It is common within long-term late effect literature for case-comparison studies to be conducted, which means that survivors of childhood cancer are compared to healthy

peer or sibling groups, particularly so in regards to physical development or various health-related issues (Mulrooney *et al.*, 2009; Robison *et al.*, 2009; Geenen *et al.*, 2010; Schwartz *et al.*, 2010; Whelan *et al.*, 2010). Recently, Schwartz and colleagues (2010), for example, used the Health Knowledge Inventory, a checklist of 35 health problems, to compare the self-reported health problems of a cohort of young adult survivors of childhood cancer (n=156) with a cohort of young adults without a history of a chronic health condition (n=138). Findings revealed that the survivor group reported significantly more health-related problems than the healthy control group (Schwartz *et al.*, 2010). The use of an unrelated control group, unlike a sibling control group as in the CCSS programme, was considered beneficial by the authors of this study, particularly as this provided additional clinical information about how survivors of childhood cancer compare to peers of a similar age and not only against siblings. This latter group are considered by some to not actually truly represent healthy and unaffected individuals, as siblings, too, can experience psychological distress and negative health-related behaviours as a result of their sibling's illness (Di Gallo, 2003; Butler and Copeland, 2006; Alderfer *et al.*, 2010; Schwartz *et al.*, 2010). Furthermore, the findings revealed that the reported problems of the survivor group were deemed to be sufficient enough to warrant significant medical monitoring or intervention, with pulmonary, cardiac, kidney and growth issues just some of the concerns identified (Schwartz *et al.*, 2010). Although significant in terms of reiterating the importance of LTFU for survivors of childhood cancer, the results should be interpreted with some caution, as only one part of the developed outcome measure was actually used in this study and there was no apparent validation of the measure prior to use in the study, following its development from clinical expertise and literature reviews.

The health status of survivors of childhood cancer and their quality of life have also been prioritised in a Swedish context of late (Sundberg *et al.*, 2010). As with previous work discussed thus far, Sundberg *et al.* (2010) adopted a quantitative case comparison study to explore the lives of a population of survivors of childhood cancer. In terms of health status and quality of life, it emerged that the young adult survivor group reported comparable levels to the control group, a finding which was also mirrored in their later findings in terms of sexual functioning (Sundberg *et al.*, 2011a).

Whilst encouraging in terms of offering some reassurance for the potential for the quality of life of survivors of childhood cancer not to be impeded by their experiences of childhood cancer, such findings should be considered in light of the lack of participation by 30% of the young adult survivors initially drawn from the regional cohort from where the included sample in the study were drawn. Furthermore, such findings should also be considered within the Swedish context from where participants were drawn, which may limit their generalizability to a wider population.

Considering physical late effects of treatment such as those raised in this section is important as it is thought that as many as two-thirds of survivors of childhood cancer will experience a secondary late effect from treatment (Oeffinger, 2004). Similarly, data from the Childhood Cancer Research Group and the West Midlands Cancer Intelligent Unit revealed comparable secondary late effect figures in a UK context, through a population-based study conducted by Curry and colleagues (2006) in one area of England. Although much smaller in sample size than the data which informed Oeffinger's (2004) conclusions, the findings from Curry and colleagues (2006) still revealed that 80% of the patients on clinical follow-up had at least one recorded health problem, as did 55% of the patients on postal follow-up in this study (Curry *et al.*, 2006). Whilst findings such as these are important in terms of reinforcing how LTFU can help provide information on late effects to those who devise treatment protocols (Curry *et al.*, 2006), there is also the need to consider psychosocial long-term late effects that survivors of childhood cancer may experience.

To summarise, the studies discussed in this section have tended to focus purely on health and physical late effect consequences of childhood cancer diagnoses and treatments, and have tended to do so primarily through quantitative, case comparison studies. As revealed in this section, there is a tendency for such studies to focus on and prioritise the medical and disease-related aspects of surviving childhood cancer, as reflected within much of the empirical base considered here. However, progress is still required in terms of ensuring patient experiences are reflected in future service design and delivery. Development of future services needs to be cognisant of the experiences of survivors of childhood cancer of not only physical late effects people may

experience, but also associated psychosocial late effects. As such, psychosocial late effects will now be considered.

2.6.2.2 Psychosocial late effects

Late effects of treatments for childhood cancer are not limited to physical health, as numerous psychosocial late effects may, too, be associated with the cancer experience and the treatments received. Psychosocial consequences can, like their physical counterparts, impact on the quality of life of survivors of childhood cancer (Levitt and Eshelman, 2008), but, unlike physical long-term late effects, these tend to be less well understood (Stam *et al.*, 2005; Marsland *et al.*, 2006). Indeed, psychosocial consequences of childhood cancer tend to be variable and can include: academic problems; delayed marriage; challenges to career and employment opportunities; apprehension about developing long-term relationships; deficits to memory, attention and learning abilities; impact on people's body image, their social relationships and independence; and impact on their insurance and access to health care (Reaman *et al.*, 1993; Bradwell and Hawkins, 2000; American Academy of Pediatrics, 2009; Hill *et al.*, 2003; Eiser *et al.*, 2007; Robinson *et al.*, 2009; Stern *et al.*, 2010; Kunin-Batson *et al.*, 2011). In fact, some consider the life of a child to be permanently changed when diagnosed with cancer and advocate for the child and their family to be supported to return to a society which heralds good health and appropriate performance (American Academy of Pediatrics, 2009). Thus, appropriate LTFU services are deemed to have a significant role in the provision of support and education of this nature, with regular review of neurological function considered to be a central part of routine follow-up for survivors of childhood cancer (Scottish Intercollegiate Guidelines Network, 2004).

However, developing an understanding of the psychosocial consequences of childhood cancer is, at times, complicated by inconsistent findings and deficient methodologies, meaning that comparisons across studies can be difficult due to variability in study designs, sample demographics, age at diagnosis, number of years since diagnosis and treatment completion, and cancer diagnoses (Marsland *et al.*, 2006). As with approaches adopted to understand physical late effects in survivors of childhood

cancer, psychosocial consequences of childhood cancer tend also to be explored comparatively, as it is considered that including demographically similar peers or healthy siblings allows potential variations between those who have experienced cancer, and those who have not, to be explored (Robinson *et al.*, 2009). Indeed, this was the approach adopted by Robinson *et al.* (2009) in their study which sought to examine family predictors of distress among survivors of childhood cancer and their parents with matched comparison group of peers and their parents in their developmental transition towards adulthood. By assessing families during treatment and again after survivors reached 18 years of age (Robinson *et al.*, 2009), it was revealed that survivors of childhood cancer and their families in this study were very similar to the group of comparison peers in most areas of psychosocial functioning assessed. However, as only the parents completed two of the same measures from the baseline period of assessment again at follow-up, with two new measures completed by the young adults at this latter stage, these findings should be treated with some caution as this weakens some of the longitudinal claims posited by these authors.

In contrast, Stam and colleagues (2005) found the course of life of young adult survivors of childhood cancer was hampered, in comparison to a group of healthy peers, despite not focusing specifically on psychosocial functioning like Robinson *et al.* (2009). In their study of Dutch survivors of childhood cancer (n=353) and a comparison group (age range of all participants 18 – 30 years) of peers with no history of cancer (n=508), Stam *et al.* (2005) found that the group of young adult survivors achieved fewer, or achieved them when older, life milestones than the comparison group in relation to the broad thematic areas of autonomy development, social development, and psychosexual development explored in the course of life questionnaire used in the study. However, despite sound validity and reliability of the measure used, it should be noted that such a questionnaire appears only to have been used within a Dutch population, thus the applicability of the measure and generalizability of the results to wider populations of survivors of childhood cancer is yet unknown. Nevertheless, the results from this study highlight the importance of ensuring that services are designed to reflect the full extent of the needs of survivors of childhood cancer.

In a recent body of work conducted to investigate the current lives of Swedish young adult survivors of childhood cancer (Sundberg *et al.*, 2009; Sundberg *et al.*, 2010; Sundberg *et al.*, 2011a; Sundberg *et al.*, 2011b) Sundberg and colleagues (2011a) have demonstrated that, on the whole, the young adult group of survivors and a comparison group of healthy peers from the general population reported similar experiences of sexuality and partner relationships. Using a 30-item self-reported questionnaire validated within a Swedish population, the authors reported that whilst similar experiences were reported between the groups, the group of male survivors were actually less likely to feel sexually attractive and had less experience of sexual partners then their comparison group counterparts. Furthermore, the female young adult survivors were less likely to be in a current relationship than the comparison group and less likely to have had sex with a partner in the last 12 months. Therefore, the authors' interpretations that survivors of childhood cancer have similar experiences to a comparison group must be interpreted with some caution, particularly as the tool used was non-standardised (Sundberg *et al.*, 2011a) and used only within the context of a Swedish population. In addition, methodologically, this study relied on cross-sectional work, which meant it offered little opportunity to determine causal relations over time; a limitation which could have been addressed by longitudinal work (Eiser *et al.*, 2000).

In summary, the empirical studies reviewed here indicate that the experiences of survivors of childhood cancer in relation to the psychosocial late effects they may experience as a consequence of their cancer and associated treatments tend to be considered through the use of quantitative methods of data collection. As with studies which seek to explore physical late effects this same population may experience, the methodological approach of choice tends to be case comparisons. Whilst beneficial in capturing the experiences of large numbers of participants, by this same token, little opportunity exists to explore individual experiences in any real depth or detail.

2.7 Survivors of childhood cancer, long-term follow-up and transition

The need for appropriate long-term follow-up care for survivors of childhood cancer has been illustrated within earlier discussions surrounding the risks of physical and psychosocial late-occurring problems these young people may face. The discussion thus far has focused on the provision of this care, and that of acute care, within a paediatric oncology setting. However, as survivors of childhood cancer age, it is likely that the continued provision of long-term follow-up care will move elsewhere (Henderson *et al.*, 2010a). Indeed, in recognition of the distinctive needs of young people with cancer, the provision of age-appropriate care has gathered momentum in recent years, with some debate as to where such care should be provided and by whom (Reaman *et al.*, 1993; Zebrack *et al.*, 2004; Aslett *et al.*, 2007; Skinner *et al.*, 2007; Absolom *et al.*, 2009). As young people grow older, they 'age out' of paediatric care, with this becoming an age-inappropriate environment in which to continue to attend for their long-term follow-up care. Therefore, young people will, at some stage, move to the adult sector to receive this long-term follow-up care (Schwartz *et al.*, 2010).

However, this movement consists, or should consist, of more than simply transferring from one institution to another; transition is a process, thus a young person's physical, social and psychological development should be reflected and encouraged throughout (Crowley *et al.*, 2011). Problems associated with the transition of survivors of childhood cancer to adult health care have, however, been acknowledged previously (Nelson and Meeske, 2005), as have the challenges of providing long-term follow-up care, particularly as this is a relatively new field with much still unknown as survivors enter middle age and older adulthood (Nelson and Meeske, 2005). Indeed, it is the transition from paediatric to adult cancer care for long-term follow-up that provides the focus for the current research. Chapter 3, which follows, discusses and explores the issue of transition in greater depth and detail, and further establishes through this discussion the need for a study such as the one explicated in this thesis.

Moreover, the need for a study such as the one of concern in this thesis is further augmented by the need to better understand the experiences of survivors of childhood

cancer, particularly so in the context of this study, of their experiences of the transition process of moving from paediatric to adult cancer services. Prioritising experiences in this way is necessary in light of the paucity of empirical studies which have considered the provision of transitional care services from the perspectives of survivors of childhood cancer; Aslett *et al.* (2007) previously noted that transitional models of LTFU were predominately discussed within the commentary papers and only one of the empirical studies they reviewed. Notably, however, the reviewed empirical study considered health care professionals' views of follow-up care, not patients'. Yet, Kelly and Gibson (2009, p.17) have argued that the provision of care for young people with cancer has all too often "been shaped by tradition and historical factors rather than need", so, to ensure services are actually developed based on these needs, there is a very real imperative to prioritise, explore and understand the experiences of care of young people affected by cancer (Aslett *et al.*, 2007; Kelly and Gibson, 2009). The provision of transitional care is one such priority, thus its precedence in the current study.

Indeed, recognising, listening to and learning from the experiences of young people is vitally important in the provision of LTFU care, as Gibson *et al.* (2005a) highlighted in a qualitative study informed by participatory methods to assess what young people receiving LTFU care would like from their follow-up service. Through a combination of participatory research methods, semi-structured interviews and postal questionnaires, the authors developed a typology of health care need, thus, in this context, what the young people in the study wanted from a follow-up service (Gibson *et al.*, 2005a). A number of categories were identified as being fundamental to the construction of this typology: need for a positive relationship with health care professionals; need for information; need for communication; need for parents to be supported; and need for health care professionals to have appropriate knowledge (Gibson *et al.*, 2005a). Whilst the construction of such a typology has the potential to inform a number of service provision developments for young people affected by cancer, one of which, as Gibson and her colleagues (2005) noted, is the development of transitional packages of care, response rates in this study were relatively poor, meaning contributions from further young people may be required to ensure completeness of the typology (Gibson *et al.*,

2005a). Nevertheless, Gibson *et al.* (2005) went some way to ensure that the needs of young people who regularly attend their LTFU appointments and those considered non-attenders were represented in the typology, by recruiting young people from both groups. However, contributions from young people considered to be non-attendees were purely questionnaire-based, despite attempts from the authors to engage this population in the workshops or semi-structured interviews. Whilst the questionnaire contained both open and closed questions, it is possible that the experiences of this population were not explored in the same depth as the attending group, as those young people engaged in participatory research methods in the workshops or semi-structured interviews. This method may have influenced the typology generated.

Certainly, within the context of LTFU, there is a need to ensure young adult survivors of childhood cancer do have particular information available, especially so to ensure that they are knowledgeable about their disease and illness history (Henderson *et al.*, 2010a). This issue becomes particularly vital when considered within the context of the process of transition and moving from paediatric to adult care to continue to receive this long-term care. It is crucial that young people are familiar with their own health maintenance needs, potential health risks, health-related behaviours and necessary ongoing screening within the context of their long-term follow-up care (American Academy of Pediatrics, 2009). Elements such as these should constitute part of pre-transition planning as survivors of childhood cancer age out of paediatric oncology health services (American Academy of Pediatrics, 2009).

However, transition planning in an oncology context such as this may first require considerably more input. In their study to obtain an overview of psychosocial support provided by paediatric oncology treatment centres across the UK, Mitchell *et al.* (2005) found that in the 23 centres who responded (24 were invited), there were considerable levels of variability in terms of transitional care processes. Within the context of young people who have completed treatment, it was found that 10 centres did not transfer the follow-up care of their patients to the adult sector. At those centres actively engaged in transitional care processes, set age ranges of the actual transfer to adult care varied from 14 years to 23 years old, with two centres not

specifying set ages at which this takes place. Notably, none of the centres had any written, formal or agreed policies or procedures in place for this aspect of care provision (Mitchell *et al.*, 2005).

Reviewing the literature here on survivors of childhood cancer, long-term follow-up and transition, it is apparent that there are a number of limitations across this body of work. The most significant and prevalent limitation is the extent to which the individual perspectives and experiences of survivors of childhood cancer of transitional care particularly have been neglected thus far. Although a number of important insights have been revealed about the experiences of this population in the context of long-term follow-up, typically such revelations are by manner of quantitative methods of data collection, in which conclusions are drawn against groups of healthy comparison peers or sibling groups. Such approaches can limit the depth of understanding about the experiences of survivors of childhood cancer, with the variability of applied outcome measures inhibiting the drawing of any definitive conclusions.

Having considered some of the clinical aspects of the childhood cancer and survivorship experience, it is timely to now consider the nature of paediatric oncology care, prior to moving towards a detailed discussion and investigation of the concept of transition in Chapter 3 that follows.

2.8 The nature of paediatric oncology care

The ethos of paediatric settings, regardless of speciality, differs fundamentally to that of adult settings, as in paediatric settings the health focus of an individual is very much viewed within the context of their family (Sawyer *et al.*, 1997), whereas in adult care patients are expected to be fully autonomous individuals considered capable of receiving and understanding information and making their own decisions about their health care (Watson, 2005). Fundamentally, as Watson (2005) postulates, the culture of support differs somewhat between paediatric and adult care settings. Although he drew such a conclusion through a consideration of the differences between paediatric

and adult renal care, a number of the issues he identified are transferable to other speciality contexts. For example, as with paediatric renal care, paediatric oncology care, too, places a significant emphasis on the family and their role within the illness experience. Indeed, within paediatric oncology care, there is a recognition that both children and families may experience adverse physical and emotional effects of treatments, during treatment and during follow-up (Eiser *et al.*, 2007). In addition, just as in the renal settings Watson (2005) describes, in paediatric oncology settings, care is also provided by a multidisciplinary team, allowing the various psychosocial needs of the patient and their family to be addressed. The recognition of this need is reflected in the nature of the multidisciplinary structures commonly observed across the 21 paediatric oncology treatment centres around the UK, as within these, social workers, play specialists and paediatric oncology outreach nurses (POONs) are commonly employed (Mitchell *et al.*, 2005). These paediatric oncology treatment centres also provide a range of services and facilities to families with a child diagnosed with cancer, typically: family accommodation in which a child's family can reside during their child's treatment; a range of accessible information and advice on matters such as finance; and psychosocial support, either from psychological or counselling services (Mitchell *et al.*, 2005). Finally, in a slight departure from Watson's (2005) observations is the notion that within paediatric oncology care, quality of survival is deemed to be a central tenet of this care, so there is a greater emphasis on the family, their role and developmental issues affected by the illness (Eiser *et al.*, 2007). This emphasis differs to adult oncology environments, as typically the focus there is on treatment commencement without consideration of potential adverse late effects, yet this common characteristic of paediatric oncology is now increasingly being regarded as central to adult oncology, too (Eiser *et al.*, 2007). Given many of the unique elements of the nature and ethos of a setting such as paediatric oncology, it is possible that involvement with such a service can, in many ways, define the experience of childhood cancer, for young people, parents and health care professionals alike.

The experience of childhood cancer can, for example, be defined by the relationships that young people and their families establish and maintain with their health care professionals in the paediatric oncology setting. Often, these relationships are

reciprocated. Bradwell and Hawkins (2000), for example, talk of continued involvement from their staff team in parents' and families' lives, following treatment cessation. Similarly, Harrington *et al.* (2009) explored the significance of relationships between paediatric oncology health care professionals and children and families. In their phenomenological study, they asked paediatric oncology clinic staff to provide written answers to eight open-ended questions so they could explore the issue of culturally competent therapy within a paediatric cancer treatment context. Despite neglecting to use interviews to gather their data, meaning they were unable to explore the phenomenon with their participants in any depth or detail at an individual level, analysis of the written responses revealed the significance of the relationships established between families and professionals, both during and beyond treatment for childhood cancer. Participants considered their relationships with families to be valuable, personal and a privilege to hold, with such relationships often maintained long-term, particularly as families often returned to the clinic to visit staff and keep staff abreast of milestones within the children's and their families' lives (Harrington *et al.*, 2009). Furthermore, the value families place on these relationships was reflected in the next generation of some families, with new babies named after members of the treatment team (Harrington *et al.*, 2009). Whilst powerful in demonstrating the nature of relationships between health care professionals, patients and families, by exploring these only from the perspectives of the health care professionals we are unable to draw any comparative conclusions on the significance of these relationships from the perspectives of young people and their families.

The nature of the relationships between young people, their families and paediatric health care professionals have been considered by some to be so powerful that there may be a sense of induced dependency of young people and families on the health care professionals and overprotection of the health care professionals of young people and their families (Bradwell and Hawkins, 2000). Similar to Harrington *et al.'s* (2009) findings, in that the likelihood of extended relationships between young people, families and health care professionals was identified, Bradwell and Hawkins (2000), discuss the informal 'friendly' relationships their staff team have with families post-treatment. Whilst such discussions appear not to be drawn from any empirical

evidence, merely their own clinical observations, these authors do question whether this over-involvement serves to further induce dependency from the families on hospital staff.

However, induced dependency is not only an issue that has been raised within the context of the dyadic family and health care professional relationships, but so, too, in the context of the relationships between young people and their parents. It has been considered by some that issues of dependency and overprotection can affect many aspects of the young person's life (Bradwell and Hawkins, 2000), and, particularly so for survivors of childhood cancer, can extend beyond treatment completion, far into long-term follow-up (Bradwell and Hawkins, 2000). It is possible that young people may become dependent on others if they are overprotected by their parents or if their normal development is stunted because of the cancer illness (Bradwell and Hawkins, 2000).

Parents do, nonetheless, have a considerable role within paediatric care, with acceptance over the years that parental involvement is an essential quality of care and has long been an accepted feature in the care of hospitalised children (Callery, 1997). Within a paediatric oncology care context, certainly, evidence has suggested the feasibility of parents' involvement in treatment decision-making (Hinds *et al.*, 2000), with parental involvement extending to contributions to treatment decision-making at the time of diagnosis (Pyke-Grimm *et al.*, 2006) and participation in clinical research trials (Woodgate and Yanofsky, 2010). Despite these findings, in their recent study to explore parents' information needs and their involvement in decision-making processes affecting the care of their children diagnosed with cancer, McKenna and colleagues (2010) found that treatment participation decisions were still heavily weighted towards doctors, with 62.4% of treatment decisions made by the clinicians. Parents expressed a desire to participate more in the decision-making processes more than they were able to and a preference for less doctor participation in this process (McKenna *et al.*, 2010). However, the limited period of the cancer experience that the authors focused on – 55% of parents who participated had a child who was at least one year post-treatment – means the preferences for involvement of parents at later

stages of the cancer experience, including periods of recurrence, were not explored. It is possible that parental decision-making preferences may alter at different stages of the childhood cancer experience, particularly as the young person ages, but McKenna *et al.'s* study (2010) was unable to compare parental decision-making in the first year following diagnosis to later stages of treatment or within the long-term follow-up period, which may involve decisions associated with possible long-term late effects the young person lives with. Notably, though, the involvement of young people at any stage of the decision-making process was neglected entirely within this study.

As previous discussion revealed, the provision of appropriate psychosocial support for children with cancer and their families is fundamental to the ethos of paediatric oncology care. In their study to assess the provision of such psychosocial support, Mitchell *et al*. (2005) surveyed 21 UK paediatric oncology treatment centres and three separate Teenage Cancer Trust (TCT) units about the psychosocial support offered by their centre. This survey, which included responses from 23 of the 24 surveyed centres, revealed some consistency across the centres, but also identified a number of areas of greater variability. The survey revealed that consistently similar services were provided across the centres, including the employment of play specialists, social workers, paediatric oncology outreach nurses (POONS) and the provision of family accommodation (Mitchell *et al.*, 2005). However, five key areas of greater variability were identified, including poor provision of counselling and psychological support and the paucity of transition support practices recorded in writing (Mitchell *et al.*, 2005). Whilst findings such as these are important to highlight potential improvements to the design and delivery of services within a paediatric oncology context, the authors also considered the findings emphasized the need to develop more formal policies and to agree standards across all centres, thereby ensuring equity of care provision. Furthermore, any improvements made should be cognisant of the lack of data from young people and parents who use the services. Indeed, recent policy developments state that reflecting patient experience in the design and delivery of services is essential to ensure such services meet the needs of young people (Department of Health, 2007b; The Scottish Government, 2008b), but this is an issue missing in the work of Mitchell (2005) and his colleagues.

The nature of paediatric oncology care is important, not only within the context of the acute care of children and young people diagnosed with and treated for cancer, but also within the context of their long-term follow-up and survivorship. As discussed previously in section 2.6 for survivors of childhood cancer, the survivorship period is the longest part of their experience, thus they can have contact with the paediatric oncology environment for many years following treatment completion. However, remaining within the paediatric care environment beyond the period it is considered developmentally for can mean such young adults do not receive developmentally or medically optimal care (Schwartz *et al.*, 2011). Therefore, an appropriately managed departure from that paediatric environment is regarded as essential, although few theoretical models or assessment tools actually exist to help facilitate this transfer to adult care successfully (Schwartz *et al.*, 2011).

2.9 Chapter Summary

This chapter has outlined the unique features of childhood cancer, including diagnostic rates, diagnoses and treatments. The impact of a cancer diagnosis in childhood has also been demonstrated, with a particular focus on the period of survivorship. The wide-reaching and variable long-term late effects young adult survivors of childhood cancer may face have also been introduced, as has the notion of long-term follow-up care. The chapter latterly considered the need for the provision of age-appropriate care and the transition to adult care a young person must make in order to continue to receive such care as they 'age out' of the paediatric setting. The issue of transition shall now be now considered in greater depth and detail in Chapter 3.

Chapter 3 Transition

3.1 Introduction

The previous chapter considered various elements of the childhood cancer experience, including survivorship and long-term follow-up care. Discussion in that chapter highlighted the importance of the provision of age-appropriate and transitional care arrangements for survivors of childhood cancer and their families. The current chapter considers transition in more detail, beginning with an overview of the conducting of the literature review, followed by a discussion of the various definitions of transition focusing on the scope and boundaries of the concept as adopted within the context of the current study. The current chapter also considers policy and practice principles of transition and empirical evidence pertaining to the process of moving from paediatric to adult care, as well as models of transitional care. An experiential focus is embedded in the critique throughout.

3.2 Conducting of the literature review

The literature review was informed by systematic methods and techniques for searching, appraising, selecting and extracting relevant information to produce a critical summary. Key search terms were identified from the aim and research question guiding this study and are illustrated in Table 2, as are details of electronic databases accessed. All searches were restricted to English language and limited to 1998-2008, updated to 2012, to take into account the increasing numbers of survivors of chronic childhood illnesses over the past two decades (Stam *et al*., 2006). Quality assessment was ensured by developing a specified search strategy and comprehensive data extraction from each paper, which tabulated extracted data by author, year, the illness the paper focused on, country, sample, methods, key findings and strengths and weaknesses of the study.

Table 2: Search terms and databases

Search Terms	Database
Adolescent health services Models Programme Initiative Transition Evaluation Cancer/neoplasms Experiences Long-term late effects Long-term follow-up Survivorship	OVID Web of Science ASSIA Medline PsycINFO

3.3 Defining terms and exploring the concept

The term 'transition' has a variety of applications. It is a noun derived from the Latin verb *transire*, to go across, thus *"the process or a period of changing from one state or condition to another"* (www.oxforddictionaires.com), invariably suggesting a relationship between change and development (Chick and Meleis, 1989). Although specific definitions of transition are modified depending upon the disciplinary focus to which the term is applied (Kralik *et al.*, 2006), there is some consensus that transition concerns people's responses during a period of change (Eccles and Midgley, 1989; Kralik *et al.*, 2006; Schumacher and Meleis, 2010). This period of change means that transitions, in whatever context they are situated, may be considered stressful experiences for individuals "because they present adaptational challenges, frequently evoke anxiety, and require a period of readjustment" (MacLean *et al.*, 1996, p.1341). Yet, regardless of the change that requires the period of readjustment, it is generally accepted that a number of overarching characteristics of transition are applicable (Meleis, 2010b), such as the passage over time in which transition occurs, and changes and adaptations that are developmental, personal, situational, environmental or relational in nature (Kralik *et al.*, 2006; Meleis, 2010a).

Despite similarities with such defining characteristics, a variety of disciplinary foci of the concept of transition do exist, which means there are a variety of context-

dependent definitions in which the term has been used. In the context of this thesis, the concept has particularly evolved within the health and social science disciplines over recent years, with understandings of the concept in these contexts largely borne from increased awareness of the linkages between the transition process and adolescent development (Kaufman, 2006).

However, in its more general form, the concept of transition in health care has gained momentum, demonstrable in the growing body of definitions of the concept that span health care literature over some 30 years or more. From early definitions of transition coined by Morris (1979, cited by Schumacher and Meleis, 2010) and Chick and Meleis (1986) to more recent conceptualisations by van Loon and Kralik (2005), consistent central conditions which influence transition have been noted, such as meanings, expectations, environment, level of planning, level of skill and knowledge and emotional and physical well-being (Schumacher and Meleis, 2010). Such defining characteristics were reflected in an early definition of the concept coined by Chick and Meleis (1986), when they sought to consider transition from a health and illness perspective. Chick and Meleis (1986) were cognisant of the notion of transition in developmental, stress and adaptation theories, but they sought to advance their conceptualisations of transition further by encompassing responses to the concept that consequently become manifested in health-related behaviours. Therefore, they defined transition in the following way:

> *Transition, as passage from one life phase, condition, or status to another, is a multiple concept embracing the elements of process, time span, and perception. Process suggests phases and sequence; time span indicates an on-going but bounded phenomenon; and perception has to do with the meaning of the transition to the person experiencing it […] In summary, transition refers to both the process and the outcome of complex person-environment interactions. It may involve more than one person and is embedded in the context and the situation. Defining characteristics of transition include process, disconnectedness, perception, and patterns of response.* (Chick and Meleis, 1986, p.239)

This definition was the culmination of a collection of work conducted by Meleis and her colleagues (Meleis, 1971; Meleis, 1975; Meleis and Swendsen, 1978) that prioritised the nature of human experiences of transitions through research and theoretical explorations. As a result, Meleis *et al.* (2010) sought to advance these explorations by undertaking a concept analysis of transition to develop typologies of transition. In so doing, a perspective and framework which would create meaning of the concept in the context of a number of changes was developed. These changes, according to the typologies, were deemed to be developmental, situational, health-illness and organisational in nature (Kralik *et al.*, 2006; Schumacher and Meleis, 2010). This literature review led to a proposal that people can undergo more than one transition at any one time, but there is an imperative for individuals to be aware of the changes so they may engage with them (Meleis *et al.*, 2010; Schumacher and Meleis, 2010). It is important to note, however, that although the proffered typologies are important in terms of advancing the argument of the central importance of transition, these typologies were identified purely within a nursing context, as the limited parameters of the review meant only nursing literature was sourced and reviewed.

Further discernible within Chick and Meleis's (1986) theorising of transitions is the sense of positivity that surrounds the process. For these authors, completion of a transition suggests that the person has reached a period in which greater stability is achieved compared to their pre-transition state. Similarly Kralik and her colleagues noted a process of change intertwined with transition. They too, developed a working definition of transition drawn from the findings of their research (Koch and Kralik, 2001; Kralik, 2002; Kralik *et al.*, 2003; Kralik *et al.*, 2006) that explored the transitional experiences of women with chronic illnesses and women survivors of child sexual abuse. They, too, consider transition to be a process; one in which women are able to examine the nature of the changes in their lives:

> *We have come to understand transition to be a process which can be a convoluted passage during which the woman redefines her sense of self and redevelops self agency in response to various disruptive life events.* (van Loon and Kralik, 2005, p.130)

Whilst consistent in their fundamental underpinnings, these two cited definitions of transition do not have direct applicability to the situational transition of concern in the current study, but are important for contextual purposes. Chapters 1 and 2 introduced how the current study is concerned with the experiences of the process of transition from paediatric to adult cancer services of young people, their friends or family members, health care professionals and case note information, with a case study based approach adopted for this exploratory piece of work. It may, therefore, be considered that the two definitions of transition previously cited in this chapter neglect some of the specificities associated with a health care transition of this nature, as they fail to reflect the evolving nature of the young person's own developmental stage and their experience within the paediatric environment and within the context of his or her illness experience.

In response, it was considered whether a definition of transition specific to a health care context like this existed within the literature. Moreover, such a definition was sought in light of the interweaving concerns, complexities and challenges that may temper a transition from paediatric to adult health care for young people living with a childhood onset chronic condition (Blum *et al.*, 1993; Forbes *et al.*, 2002; Rosen *et al.*, 2003; Betz, 2004a; While *et al.*, 2004; McDonagh, 2005). Further, as transition from paediatric to adult care is now seen as particularly important in light of the increasing numbers of young people living into adulthood with conditions once considered fatal (Stam *et al.*, 2006), a definition which recognised the uniqueness of a health care transition, in which there is some movement from paediatric to adult services, was considered particularly applicable to this study.

3.3.1 Transition from paediatric to adult care

The concept of moving young people's health care from the paediatric to the adult setting is not new, as for several decades, this has been regarded an accepted element of health services and health care delivery (Rosen, 1993; Blum *et al.*, 1993; American Academy of Pediatrics *et al.*, 2002; Rosen *et al.*, 2003). In fact, momentum has gathered in this area to such an extent that a health care transition from paediatric to

adult care, the premise of which should ensure young people are able to receive their ongoing and long-term term care in an age-appropriate environment, has increasingly been considered vital at both an empirical (Betz, 1998; Betz, 2004b; While *et al.*, 2004; Lotstein *et al.*, 2005; McDonagh, 2005; McCurdy *et al.*, 2006; Knapp *et al.*, 2008) and policy (Royal College of Nursing, 2004; Royal College of Nursing, 2008; Royal College of Physicians of Edinburgh, 2008) level. The importance of transition is further illuminated by improvements in survivorship rates for conditions initially considered fatal in childhood; such advances stressed the importance of providing appropriate support and services to help young people with special health care needs achieve their full physical, social and psychological developmental milestones (While *et al.*, 2004).

Thus, in a departure from the two definitions of transition cited previously in section 3.3, an alternative definition which, in many ways, was deemed to better reflect the focus of the current study, was identified. The appropriateness of this alternative definition is obvious, not only because of its specific applicability to the situational transition of concern in this study, but also because the complexities of the simultaneous nature of the process of transition between health care services and co-occurring life-stage transitions (Reiss *et al.*, 2005) are honoured. Thus, the definition of transition adopted in this study is that posited by Blum *et al.* (1993):

> *A purposeful, planned process that addresses the medical, psychological and educational/vocational needs of adolescents and young adults with chronic and medical conditions as they move from child-centred to adult-orientated health care systems.* (Blum *et al.*, 1993 p.570)

Resulting from work conducted in the early 1980s in the USA, the definition was devised following a series of conferences in which it was recognised that transition was the one major issue that had not been addressed for young people living with chronic conditions (Blum *et al.*, 1993). At that time in the USA, the health care system was identified as a barrier for young people living with chronic conditions, as it did little to facilitate their attempts to access developmentally appropriate health care (Blum *et al.*, 1993). Consequently, a collaborative working meeting on transition in the early

1990s between three large American professional bodies - the Society for Adolescent Medicine (SAM), the National Centre for Youth with Disabilities (NCYD), and the Maternal and Child Health Bureau (MCHB) – permitted the detailed discussion of key issues for young people living with disabilities (Blum *et al.*, 1993). This led Blum and colleagues (1993) to coin the definition of transition cited previously.

Subsequently, this definition of transition has been widely adopted and accepted within the literature and across illness contexts both nationally and internationally (Callahan *et al.*, 2001; Shaw *et al.*, 2006b; Bolton-Maggs, 2007; Steinbeck *et al.*, 2008; Baines, 2009; Brooks *et al.*, 2009; White and Hackett, 2009; Fredericks *et al.*, 2010; Schwartz *et al.*, 2011). No distinct definition of a health care transition that involves a movement from paediatric to adult care is apparent specifically within a UK or a wider European context, as empirical papers and governmental policy documents alike typically cite the Blum *et al*. (1993) definition for contextual purposes (Department of Health, 2006; Robertson *et al.*, 2006; Lundin *et al.*, 2007; Royal College of Physicians of Edinburgh, 2008).

The widespread acceptance of the Blum *et al.* (1993) definition of transition means there has rarely been any critique directed at its construction or applicability to the patient population to which it refers. However, the most significant criticism that can be levied at the definition is the extent to which patient experience informed its development and construction. To clarify, it is difficult to discern whether young people living with disabilities and their families were included in the discussions at the various collaborative working meetings in the USA, during the period where transitional care arrangements gathered momentum. To demonstrate, within Blum *et al.'s* (1993) narrative, they refer only to "representatives of the major medical associations and organisations" (Blum *et al.*, 1993 p.571) as having a contributory role in the development of the definition of transition. It is, therefore, plausible to conclude that the resultant definition and subsequent conceptualisations of the process of transition have been drawn purely from expert opinion and not in collaboration with young people and families. Moreover, it is probable that the now widely accepted and applied definition of transition was constructed with little direct

understanding of young people's and parent's actual experiences of what it was like to move from paediatric to adult services. Regrettably, despite some several intervening decades, this paucity of experiential influence appears to remain the status quo given the absence of any definitional progression.

Nonetheless, there has been some evolution in the extent to which simultaneous developmental experiences are raised as priority issues within the context of a health care transition from paediatric to adult care. In particular, a subsequent consensus statement on transition endorsed by the American Academy of Paediatrics, the American Academy of Family Physicians and the American College of Physicians-American Society of Internal Medicine was created following a consensus conference held in 2001 to improve transition (American Academy of Pediatrics *et al.*, 2002; Rosen *et al.*, 2003). Once again though, the consensus statement developed in the USA and the description of the goal of transition that evolved were devised without the input of any young people living with chronic conditions or their families, as the conference consisted of an entirely professional delegation. So, although an evolved description of the goal of this kind of health care transition was successfully developed, we must be attentive to the lack of any definitive experiential involvement of any of groups to which it refers, during its development:

> *Transitions are part of normal, healthy development and occur across the life span. Transition in health care for young adults with special health care needs is a dynamic, lifelong process that seeks to meet their individual needs as they move from childhood to adulthood. The goal is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood. It is patient centered, and its cornerstones are flexibility, responsiveness, continuity, comprehensiveness, and coordination.* (American Academy of Pediatrics *et al.*, 2002, p.1304)

As an adjunct to the Blum *et al.* (1993) definition, the complexities surrounding a health care transition for young people with chronic illnesses are more fully revealed in

the previously cited description. There is a sense that the movement from paediatric to adult care, and its success, is tempered not only by the simultaneous developmental transitions young people experience, but so, too, by the organisational structures which facilitate this process. Taken together with the definition offered by Blum *et al.* (1993), we can see that there is a need to consider a health care transition as not merely a move from one health sector to another, but as a synchronous process. Consequently, several aspects of the consensus statement meant that it provided an appropriate framework, in combination with the Blum *et al.* (1993) definition of transition cited on page 60 previously, for the current study, including its patient focus and patient-centeredness, its recognition of the processes, planning and preparation surrounding a health care transition, and its widespread application across the body of literature, supporting its utility.

3.4 Principles of health care transition

Within the literature – empirical, non-empirical and policy – a number of defining and central characteristics of health care transition have been identified. These include: the need for planning and preparation; the provision of effective data management systems; a transition co-ordinator to liaise with the family and to ensure a co-ordinated transfer; and flexibility in the timing of the actual transfer to adult services (Viner, 2003; McDonagh, 2007; Baines, 2009; Rapley and Davidson, 2010).

As transition is now generally such an accepted aspect of health care for young people living with chronic illnesses and conditions, umbrella organisations, charities and governmental agencies have all sought to raise transition as an issue of importance in their published material (Department of Health, 2006; The Association for Children's Palliative Care, 2007; Department of Health, 2008). Whilst policy documents particularly tend to focus either on transitional care within the context of a specific condition or, on occasion, within the context of multiple conditions, referring only to diagnostic specificities in dedicated sub-sections, if appropriate, the purpose of many of these documents is typically fourfold. First of all, such documents seek to raise awareness of the key areas of concern within a transitional care context. Second,

these documents tend to provide transitional care advice and guidance in terms of service planning, organisation and delivery. Thirdly, most of the documents advocate for multi-disciplinary and multi-agency working, and finally, many embed the need to develop transitional care pathways (Department of Health, 2006; Department of Health, 2008; Department of Health, 2007a).

Within the context of the current study, though, some apparent disparity across such policy documents is worth noting. First, it is somewhat rare to find any detailed discussion of childhood cancer and childhood cancer survivorship in these documents, in either a generic transition or diagnostic-specific context. Rather, there is a tendency in some of the overarching transition policy documents to prioritise chronic childhood onset conditions, such as cerebal palsy, muscular dystrophy, spina bifida or epilepsy (Department of Health, 2008), or to adopt a broader approach in which the focus is on young people with disabilities (Department of Health, 2007a). It would seem that although there have been notable increases in survivorship figures in many conditions previously considered fatal in childhood, with childhood cancer one such example, policy rhetoric surrounding transitional care provision for this latter group remains, in some ways, more limited. As explicated previously in Chapter 2, section 2.6, it is now well known that the experience of childhood cancer can pervade people's lives far beyond the time of diagnosis and treatment (Department of Health, 2010; Gibson and Levitt, 2010a). It is possible that the disparity between conditions, such as those aforementioned and survivorship of childhood cancer, in these documents is borne from a lack of knowledge and understanding surrounding childhood cancer, survivorship and long-term late effects, as it is only relatively recently that constructions of cancer have evolved in such a way that living with cancer, regardless of the stage of life when a diagnosis is confirmed, is regarded to be a long-term condition (Department of Health, 2010).

As a result of such progress, the needs of survivors of childhood cancer have emerged as being specifically prioritised and addressed within the context of the provision of effective transition services, as noted in later and more recent publications (Royal College of Physicians of Edinburgh, 2008; Gibson and Levitt, 2010a; Gibson and Levitt,

2010b). Publications by The Royal College of Physicians (2008) and The National Cancer Survivorship Initiative (Gibson and Levitt, 2010b), for example, have not only discussed the need to consider transitional care arrangements for young adult survivors of childhood cancer, but have also provided examples of current working practices in which the principles of transition have informed the development of some of these services. However, there still remains a lack of empirical evidence to suggest the ways in which the principles of transition are being implemented in clinical practice, specifically so, ways in which people's experiences of transition in a cancer context are reflective of key principles of transition consistently outlined. Indeed, it has recently been noted that the body of empirical evidence on studies which focus on transition is somewhat smaller than that of the non-empirical work, as here, reviews, policy or position papers, and descriptions of services are more readily available (Doug *et al.*, 2011).

Yet, there is also a noted disparity in the aforementioned transition policy and practice documentation in terms of the extent to which patient experience is embedded in and has informed the development of this material. To demonstrate, such documentation can appear to prioritise service organisation in a top-down manner, with the expertise and clinical input of policy makers and practitioners driving the development of such statements and policies over the experiential input of young people and their families. For example, a focus on person-centred planning was listed fourth on a list of more than twenty characteristics of good transition services (Department of Health, 2008). Although documents such as *Transition: Getting it right for young people* and *Transition: Moving on well* (Department of Health, 2006; Department of Health, 2008 respectively) both acknowledge and raise the importance of involving young people and their parents in the development of various components of the transition process as one of the characteristics of good transition services, this is not discernible as the number one characteristic in either of these documents. Instead, addressing managerial attitudes (Department of Health, 2006) and processes for strategic planning between paediatric and adult services (Department of Health, 2008) take priority.

Encouragingly though, statements such as those proposed by The Royal College of Physicians of Edinburgh (2008) and governmental initiatives such as the *National Cancer Survivorship Initiative* (Gibson and Levitt, 2010a; Gibson and Levitt, 2010b) in England and the *Better Together: Scotland's Patient Experience Programme* in Scotland (NHS Scotland, 2012) are placing far greater emphasis on patient experience in the drive to support the delivery of improved models of care (The Scottish Government, 2009; Department of Health, 2010). This emphasis is reflected in some of those more recent practice-related developments, as there is some notable progress in terms of the ways in which patient experience is embedded within these. For example, patient experiences are prioritised, albeit from a small number of participants, in a series of recent reports relating to the development and evaluation of a neuro-oncology Teenager and Young Adult Transition Project in one area of Scotland (Bream *et al.*, 2010; Hodgkiss *et al.*, 2011), as part of the *Better Together: Scotland's Patient Experience Programme* (The Scottish Government, 2009). Similarly, in the document *Building the Evidence* produced by the National Cancer Survivorship Initiative (Gibson and Levitt, 2010a), there are a number of quotes from young people about their experiences of transition. Improvements to patient experiences as a result of developments within transitional care services at a number of test sites across the United Kingdom are also evident in this latter document, not only through young people's narratives, but also in terms of highlighting the ways in which patient experience helped inform service design.

As intimated here, a number of key principles of transition are typically outlined in documents such as those aforementioned. Whilst consistency pervades in terms of embracing key principles of transition, it seems that only rarely have these ideologies been questioned, with the 'problem of transition' only latterly debated in a diabetes context (Allen and Gregory, 2009).

Having considered the adopted definition and description of transition in section 3.3.1 and principles of transition throughout section 3.4, in sections 3.4.1 and 3.4.2 that follow, two discernible concepts which penetrate discussion thus far in the current chapter – the centrality of the young person in the transition process and the planning

and preparation that should be embedded in such a process, will be investigated by drawing on available empirical, non-empirical and policy literature.

3.4.1 Young-person-centred process

Adolescence is a period of transition from childhood to adulthood, marked by a number of key challenges, developmental milestones and changes (Kaufman, 2006). Such milestones include achieving biological and sexual maturation, developing sophisticated abstract thinking skills, developing a personal identity, establishing independence and autonomy in the context of the socio-cultural environment, the movement towards autonomy from family relationships and the development of intimate sexual relationships with an appropriate peer (Coleman and Hendry, 1999; Christie and Viner, 2005; Kaufman, 2006). However, adolescence is shaped not only by biological and psychological growth (Davis *et al.*, 1985), but so, too, by the social and cultural context in which it occurs (Crocket, 1997; Kelly, 2008). As a result, both social and cultural determinants of adolescence shape how members of this particular age group behave and are perceived (Kelly, 2008).

Therefore, developmental, social and cultural events such as these require young people living with a chronic childhood onset condition and their families to negotiate a range of interweaving experiences in the context of their health care transition. As a result, there is an expectation that health care providers ensure the delivery of appropriate transitional care in light of these co-occurring life events (Betz and Redcay, 2003; Betz, 2007). Addressing the complex web of interrelationships in the process of transition between services and transitions between life-stages for young people diagnosed with a chronic illness in childhood has been posited as a priority issue in health care in recent years (Reiss *et al.*, 2005), particularly as increasing numbers of chronically ill children are surviving into young adulthood (While *et al.*, 2004; Stam *et al.*, 2005).

In light of these complex interrelationships, it is feasible to suggest that the experience of transition impacts not only on the young person, but also their families and the

health care professionals with whom they have worked to receive their care. Yet, in terms of the evidence base, studies which have considered the process of transition from this triadic perspective are limited (Hauser and Dorn, 1999; Dupuis *et al.*, 2011). Instead, insight into these complex interrelationships has been revealed through studies which have explored the perspectives of young people individually (Oeffinger *et al.*, 2000; Brumfield and Lansbury, 2004; Kirk, 2008), or young people and their parents (Farrant and Watson, 2004; Craig *et al.*, 2007; Casillas *et al.*, 2010; Fredericks *et al.*, 2011).

Studies which have considered the perspectives of young people have reiterated the need for transition to be considered a patient-centred process. Although the concept of transition emerged within the boundaries of a wider study concerned with exploring young people's experiences of living with medical technology, Kirk (2008), for example, did note that, following in-depth interviews with 28 disabled young people aged between 8 and 19 years, a health care transition was not the only transition they experienced. Variability of the sample in terms of the disabilities young people were living with, their ages, and the associated health care technologies they used were observed, but the commonality of the dual nature of the transitions these young people experience did emerge, as their health care transition would often occur concurrently to their transition from childhood to adulthood or alongside illness transitions. However, the lack of detail on the illness-related characteristics for each young person meant it was not possible to develop an understanding of any illness-specific issues associated to their individual transition experiences, thus as a true young-person-centred process, this was limited.

In contrast, in their attempts to consider transition as a young-person-centred process, Brumfield and Lansbury (2004) conducted a qualitative study to explore the experiences of six young adults aged between 19 and 34 years living with cystic fibrosis "as they made the transition from paediatric to adult care" (Brumfield and Lansbury, 2004, p.223). Although similar in terms of the broad general areas considered to affect the experiences of transition for these individuals, the retrospective design adopted was a considerable limitation of this study. To demonstrate, within their small sample

size of six participants, the range of time since participants "had made the transition to adult care" (Brumfield and Lansbury, 2004, p.225) varied from three months to twenty years, with two participants interviewed fifteen to seventeen years following their move. These latter periods of time since transfer and participation in the interviews are notable methodological limitations of this study, as participants' accounts may have been influenced by potential recall issues and may have been subjected to significant reinterpretation over time. Further, such variations significantly limit the extent to which the findings can be generalised, due to the variability between the participants. Moreover, by consistently noting that the participants 'had made the transition to adult care' confuses the act of transfer with the process of transition. This issue is discussed again in section 3.4.2 of this chapter.

Another point worth noting in relation to the extent to which a young-person-centred approach to transition has been considered is the prominence of quantitative survey based measures to do so. Designed with the intention of developing patient-oriented transition programmes, studies like that of Fredericks *et al.* (2011), which recruited 46 young adult liver transplant recipients and 31 of their parents, have revealed that this population of young adults are aware of the importance of the transition process, but reported concern and worry about actually transferring to an adult clinic. Whilst findings such as these have informed developments of a programme for transitional care in the paediatric liver transplant clinic where these authors are based, such results should be interpreted with some caution, given generalizability of their findings is limited by the small sample size, for a purely quantitative study. In addition, the tool these particular authors used to assess patient and parent perspectives on transition was not validated; rather, it had been adapted for use in their study from its previous use with young people with sickle cell disease. Also, given the rigidity of the tool, no opportunity existed for young people or parents to report perspectives or attitudes outwith the predetermined criteria, thus a wider, detailed understanding of their perspectives was not possible.

As discussed, the process of transition from paediatric to adult care is regarded as occurring concurrently to other transitions in young people's lives. Thus, considering

young people's readiness for transition in light of these concomitant changes should be considered a central facet of ensuring a young-person-centred approach to this process (McDonagh, 2005). Transition readiness has been considered in some empirical research conducted to date. For example, studies by Wiener *et al.* (2007), McPherson *et al.* (2009), Fredericks *et al.* (2010), Schwartz *et al.* (2011) and van Staa *et al.* (2011) have considered transition readiness in populations of young people who are HIV-positive, have sickle cell disease, have received a liver transplant, or chronic conditions, respectively. Although distinct in the populations with whom they worked, typical across these studies, however, is the adoption of quantitative-based measures to assess transition readiness. Whilst important in highlighting particular elements associated with a young person process, such as young women having higher levels of anticipated difficulty with the transition than young men (McPherson *et al.*, 2009), those who are less ready for transition having higher state anxiety scores (Wiener *et al.*, 2007), and those who had a more positive attitude about transition feeling more ready to move to adult care (van Staa *et al.*, 2011), these studies do have a number of limitations that should be noted. Firstly, the relatively small sample size (for a purely quantitative study) in the McPherson *et al.* (2009) study limits the conclusions that can be drawn, as responses were received from only 72 of the 240 patients who were sent the readiness assessment questionnaire. Further, the predetermined survey questions used across the studies did not allow for young people to report the individualities of their experiences, thus limiting a truly patient-centred focus. In addition, the readiness assessment tools used in these quantitative studies were typically not validated, with the scale used by Wiener and colleagues (2007) particularly neglecting to ask about young people's readiness in respect to anything other than medically-orientated information. Indeed, it has been reported previously that no standardised, validated measurements of adolescent readiness to transfer to adult care exist (Robertson, 2006), yet a variety of measures are still used.

Within the context of chronic childhood onset conditions such as diabetes, asthma, cystic fibrosis and juvenile idiopathic arthritis, the evidence base surrounding patient-centred approaches to transition research is growing. However, there is somewhat a lack of comparable research in a cancer context; very few studies exist in this field that

have considered the process of transition from the perspective of young people (Oeffinger *et al.* 2000; Zebrack *et al.* 2004; Thompson *et al.* 2009; Casillas *et al.* 2010;). It was previously noted that a distinct lack of research which explored young people's perspectives and perceptions of their transition from paediatric to adult care existed, and available evidence lacked robust methodology (Fleming *et al.*, 2002). Currently, within a cancer context, the pertinence of such a criticism persists, thus there is the need for a study such as the one explicated in this thesis, which prioritises an experience-focused approach.

As demonstrated in Table 3 on pages 73-75, supporting the need to focus on transition in a cancer context, specifically so from an experiences perspective, are the findings from only one study (Casillas *et al.*, 2010) published in the literature to date that has adopted a qualitative approach to explore the transition from paediatric to adult care with young adult survivors of childhood cancer. Three other studies in this field (Oeffinger *et al.*, 2000; Zebrack *et al.*, 2004; Thompson *et al.*, 2009) either adopted alternative methodologies (for example, the Delphi method (Zebrack *et al.* 2004)) or did not intend primarily to explore transition, but instead discussed the concept in the context of the wider provision of long-term follow-up for survivors of childhood or adolescent cancer, thus consequently engaged with the concept (Oeffinger *et al.*, 2000; Thompson *et al.*, 2009).

Yet, as discussion in Chapter 2 revealed, transition within a cancer context is primarily concerned with the continued provision of long-term follow-up for survivors of childhood cancer. Thus, there are a number of components of the experience of this illness that warrant transitional care to be considered from the perspectives of young people, their families and health care professionals. In an attempt to address this issue, a study recently conducted in the USA by Casillas *et al.* (2010) sought to determine the perceived barriers or facilitators to the transition from paediatric to adult-centred survivorship care for a group of young adult Latino survivors of childhood cancer. They sought also to explore the parents' perspectives of care. Using content analysis, the authors reported only one facilitator to survivorship care for young people and another for parents. For young people, the facilitator was the

importance of the role of the nuclear family in survivorship discussions, whereas for parents, this was emphasis on symptom communication in the late effects discussions. Barriers to survivorship care were found to be similar across participant groups, with cancer stigma and recalling of the cancer experience as traumatic, particularly for the family from young people's perspectives, deemed applicable to both groups. Whilst some of the themes were considered to be population-specific, particularly the suggestion from both young people and parents that the word 'cancer' should be used minimally when discussing survivorship care, given the connotations this has within the Latino community (Casillas *et al.*, 2010), the findings are important as they highlight the role of parents in survivorship care. As a result, these findings further demonstrate the importance of the experiences of parents to be considered within a transitional care context. However, this study was limited by adopting a content analysis approach as, arguably, this meant only a descriptive account of the experience of the process was afforded. Furthermore, it is worth noting that none of the central characteristics of transition discussed at length in various commentary and policy documents featured at all within Casillas *et al.'s* (2010) paper.

Zebrack *et al.*'s (2004) Delphi method study, on the other hand, highlighted a number of important components of health care, types of health care providers and settings for care in the models for optimal provision of health care for young adult survivors of childhood cancer. However, it should be noted that a number of limitations surround the use of the Delphi method in this particular study. Principally, panel members were selected on a proven history of active participation in cancer survivorship and advocacy efforts at national, state or local level. Therefore, the views represented were those of this perhaps biased sample, with the key components of care in this context failing to account in any way for other young people who do not engage in active advocacy activities, or further still, do not engage with health services at all.

Table 3: Transition and cancer relevant studies

Author / Illness / Country	Aim	Sample*	Methods	Key results	Strengths	Weaknesses
Oeffinger *et al.* (2000) Cancer USA	- Describe a multi-disciplinary transition programme for survivors of childhood cancer in adult care and report late effects of survivors followed in the programme.	- N=96 young adult survivors in the ACE progamme, aged 17-34 years (median age at diagnosis 9.8 years).	- Retrospective database and medical record review. - Grading of late effects reported with the Common Toxicity Criteria (v2).	- Demonstrates the clinical benefits of an interdisciplinary transition programme for survivors of childhood cancer.	- Data for all available patients at time of study included in review.	- Not self-report. - No additional or complementary data collection methods adopted to explore young adults perceptions and experiences of the multi-disciplinary transition programme. - No additional or complementary data collection methods adopted to compare findings from medical record review with experiences and perceptions of the young adult survivors of their experience of late effects. - Small sample size = no comparisons between cancer types or length of period of long-term follow-up.
Zebrack *et al.* (2004) Cancer USA	- Explore potential barriers to long-term follow-up care for young adult survivors of	- Expert panel convened. - N=19 survivors of cancer (diagnosed before age	- Delphi study	- Number of key barriers to and initiatives to enhance care identified by the panel. - A number of components of	- Identified barriers and facilitators to care derived from perspective of young adults. - High level of completion of	- Potential sample bias = expert panel selected based on documented history of participating in survivorship or advocacy activities at national, state, or local level. - Small sample size. - Inclusion of only one parent in panel.

	childhood cancer.	30, median age at diagnosis 13.9 years). - N=1 parent of deceased cancer patient.		optimum health care and preferred sources of care identified by panel. - Findings indicate that survivors of childhood cancer want information about their medical history.	questionnaires by panel members.	
Thompson *et al.* (2009) Cancer Australia	-Explore the experiences of unmet physical, psychologi-cal and social needs amongst AYA with cancer.	- N=8 young people, mean age at diagnosis = 24.8 years.	- Qualitative. - Focus group.	- Development of a transitional care plan identified as important for future care provision – but identified in context of supporting young people during the transition from active therapy into follow-up	- Young people's experiences prioritised to inform future practice recommendations.	- Small sample size. - Only one focus group conducted. - Sample consisted of young people actively receiving treatment and people who had completed treatment. - Transition to adult care identified as a secondary issue in context of other findings.

				and survivorship care.		
Casillas *et al.* (2010) Cancer USA	- Explore the views of Latino AYA survivors and parents on how to improve the transition from paediatric to adult-centred survivorship care.	- N=27 Latino AYA survivors (aged 15-30), Mean age at diagnosis = 12 years. - N=21 parents.	- Qualitative. - Semi-structured, in-depth interviews with AYA's. - Focus groups with parents.	- One facilitator and two barriers to survivorship care identified for AYA group. - One facilitator and two barriers to survivorship care identified for parent group. - Facilitators differed between groups, but barriers the same.	- Included parents, so a number of parental specific issues identified. - Diagnoses of AYA participants mirrored the three most common diagnoses of cancers in children. - Qualitative approach = explored transition experiences in detail.	- Content analysis = descriptive accounts of experiences. - Not clear if the parent participants were parents of the AYA in this study. - Generalisability of findings outwith Latino community? - Not clear what stage of the transition process AYA and parents were at.

* Adolescents / young adults / young people / patients: terminology cited reflective of that adopted by authors in papers

Continuity has been identified as a central facet of transition (Forbes *et al.*, 2002; While *et al.*, 2004); consequently, policy argues that linked and comprehensive services should be available to help support young people throughout the simultaneous transitions of moving to the adult sector and movement towards adulthood (Department of Health, 2007a), with multi-agency working deemed to be central to ensure seamlessness during this process (Department of Health, 2008; Royal College of Physicians of Edinburgh, 2008). The literature suggests best practice entails initiation of the transition process when the young person is being cared for by paediatric services (Royal College of Physicians of Edinburgh, 2008), but this process should not cease upon physical transfer to adult services. Rather, the process should, dependent upon the young person's needs, continue for a number of years after the physical move (Department of Health, 2008). Within this context, particularly the provision of linked and continuous services, commentary, consensus and policy literature dictates that young people should be knowledgeable about where they will continue to receive their care following their departure from the paediatric setting to ensure a young-person-centred process.

Empirical evidence, on the other hand, suggests, in reality, from an experiential perspective, young people and their families are not always aware of where they will receive their care following their departure from the paediatric hospital or who will provide this care. Fredericks *et al*. (2011), for example, found that only 21.7% of their sample of adolescent liver transplant recipients and 17% of their parent sample reported knowing which hospital/doctor or clinic/provider respectively that the young person would be transferring care to. Although the authors were unable to link responses to their transition perceptions and attitudes questionnaire to issues associated to medical stability, health status or adherence for each young person, due to the anonymity of the questionnaire, these findings are important. Particularly, the findings highlight that despite best practice recommendations and accepted principles of transition, improvements can still be made to these in service provision terms to ensure a young-person-centred process is routinely adopted.

3.4.2 Planning and preparation: A process, not an event

As discussed previously in section 3.3.1, across the literature, some level of consistency is observed in relation to the adopted definition of transition, as it is virtually always regarded that transition should exist as a process, rather than a one-off event. This assumption marries well with the definitions previously outlined in section 3.3.1 of this chapter, thus supporting earlier deductions that the definition of transition coined by Blum *et al.* (1993) and the further contextual description of transition proffered by the American Academy of Pediatrics (2002), are the ones most commonly cited across these documents, and indeed much of the transition literature. Consequently, there is also some consistency within the documents in terms of the suggested foundations and principles of transition, with the need for early initiation of the process, planning and regular review of this process with the young person frequently regarded as the cornerstones of successful transition (Department of Health, 2006; Royal College of Physicians of Edinburgh, 2008). The foundations for these cornerstones have been informed largely by developmental literature, from which there has been an acknowledgement of the simultaneous life stage transitions that occur for young people during their transition from paediatric to adult care (Department of Health, 2006; Department of Health, 2008; Royal College of Physicians of Edinburgh, 2008; Allen and Gregory, 2009).

Effective means of the process of transition from paediatric to adult health care for young people with chronic conditions or illnesses are frequently debated within commentary papers in the transition field, yet the provision of such services is often supported only by limited, and at times, weak, empirical evidence (Forbes *et al.*, 2002; Tuchman *et al.*, 2008), as illustrated in Appendix 1. Available empirical evidence is somewhat varied, as the focus varies from: descriptions of expectations and perceptions of the process of transition from paediatric to adult care (Boyle *et al.*, 2001; Shaw *et al.*, 2004b; Zebrack *et al.*, 2004; Lundin *et al.*, 2007; Tuchman *et al.*, 2008; Moons *et al.*, 2009); accounts of people's experiences of health services and transition (Hauser and Dorn, 1999; Oeffinger *et al.*, 2000; Brumfield and Lansbury, 2004; Farrant and Watson, 2004; Miles *et al.*, 2004; Pacaud and Yale, 2005; McCurdy *et al.*, 2006; Visentin *et al.*, 2006; Kirk, 2008; Casillas *et al.*, 2010); satisfaction surveys and

evaluations of transitional health care (Lowton *et al.*, 2005; Remorino and Taylor, 2006; Shaw *et al.*, 2006b; Craig *et al.*, 2007); and assessments of young people's readiness for transition (Wiener *et al.*, 2007; McPherson *et al.*, 2009; Fredericks *et al.*, 2010; Sawicki *et al.*, 2011; van Staa *et al.*, 2011; Gilleland *et al.*, 2012).

By way of demonstrating the value of considering transition as a process and not an event, some studies have sought to qualitatively explore the experience of the transition process of young people. Miles *et al.* (2004), for example, sought to do this with seven young people who were HIV-positive who had transferred from the paediatric to the adult setting. Primarily retrospective in nature, during the individual interviews, young people were asked about a range of topics, which allowed the authors to present their findings within three main categories reflecting the phases of transition: preparation for transition, the actual transition and post transition. In terms of the preparation for transition, an element young people found helpful in the context of their experience were the prior introductions to adult care providers in the paediatric setting. Young people also stressed the importance of being prepared to move to an environment in which they would meet adults who were HIV-positive; a reality they had not been confronted with previously (Miles *et al.*, 2004). These authors further noted that the process of transition is important for families, too, particularly as there tends to be a shift in emphasis from a family-centred to a more individualised approach in the move from paediatric to adult service (Miles *et al.* 2004).

Studies which have sought to explore the duality of the expectations and experiences of young people and parents during transition are somewhat weak, however. One example is Boyle *et al.'s* (2001) USA-based study, which was conducted with young people living with cystic fibrosis and their parents to develop cystic fibrosis-specific transition guidelines. To do this, participants – young people and parents – completed an anonymous "pretransition" survey in the three months prior to transition. This led to the development of specific transition strategies, which were assessed for effectiveness in the "posttransition" interview 8-12 months later (Boyle *et al.*, 2001, p.429). The quantitative pre-transition survey was developed specifically for this study

and was completed by 52 young people and 38 parents. Although the survey tool was not validated, analysis did reveal the ways in which two distinct groups of individuals can have unique concerns about transition, particularly prior to the first actual attendance in the adult setting. For example, the young people in this study reported potential exposure to infection in adult care as their most important concern, whereas the primary concern of their parents was the ability of their son or daughter to manage their cystic fibrosis independently in adult care (Boyle *et al.*, 2001). The post-transition interview, which the authors actually refer to as a second survey later in their article, was completed by 60 young people and revealed that young people considered ready telephone access to a nurse, quality care and education about cystic fibrosis-related issues to be the most important expectations of an adult programme, consistent with issues identified in the pre-transition survey. Parents, on the other hand, had similar expectations of adult care, but they also considered fertility and transplant expertise to be central components of an adult programme. Whilst the study did provide some revealing experiential insights, the results are particularly limited by the absence of a robust methodology – not only did parents not complete a post-transition interview, the authors also had no way of accounting for the percentage of overlap for those young people who completed the pre- and post-transition surveys. Thus, in both respects, the authors failed in their attempts to provide insight into the expectations of young people and parents prior to and following transition to adult cystic fibrosis care.

Similarly, concerned with the ways in which the needs of young people living with juvenile idiopathic arthritis (JIA) and their parents could be addressed within a structured transitional care programme, Shaw *et al.* (2004b) sought to gain some insight into the transitional care needs of these individuals. Adopting a qualitative approach to do so, the authors conducted a four-way series of focus groups: adolescents aged 12-18 years old, young adults aged 19-30 years old, all of whom were living with JIA, parents of adolescents and parents of young adults living with JIA. In total, 53 individuals were included, a sizeable number for a qualitative study. The findings from these focus groups support key principles required for successful transitional care programmes identified in a recent literature review (Rapley and Davidson, 2010), with issues such as a multi-dimensional, co-ordinated, supportive,

and developmentally and age-appropriate programme of transitional care requested by adolescents, young people and parents alike. However, as this study was borne from a concern about the discrepancies between adolescents' actual health concerns and health care professional approaches to the design and delivery of these services, this study may have been strengthened by also including health care professional perspectives. This would have allowed the authors to discern yet further common patterns of meaning, and may particularly have allowed for revealing insights between the groups to emerge, thereby reiterating the power of prioritising the needs of young people and parents in a transitional care context from their own perspectives.

In a further study conducted with a group of young people living with JIA and their parents, Shaw *et al.* (2004a) set out to identify the most ideal programme of transitional care for this population. In one of the few studies which has sought the opinions of young people, parents and health care professionals simultaneously, these authors sought to determine expert opinions regarding best practice in transitional care provision and the feasibility of doing so within a UK context by using a modified two-stage Delphi method. The panel comprised 82 individuals at round one; 20 young people living with JIA, 19 parents and 43 providers, with a high response rate of 90% for the final panel at round two. Using a questionnaire generated from earlier work (Shaw *et al.*, 2004b), tested for face validity, respondents in round one were asked to rate to what extend they agreed each included statement represented best care, with providers additionally asked to indicate the feasibility of each of the statements. Following collation of the responses from round one, in round two, respondents were asked to re-score the items in light of the initial responses from the group, illustrated graphically to respondents at that second stage. Similar to their previous work (Shaw *et al.*, 2004b), the findings revealed six key highly feasible areas deemed to constitute best practice, including: addressing young people's psychosocial and educational/ vocational needs; an individualised approach; and honest explanations of the adolescent's condition and associated health care. Whilst these findings are important in the light of the study's success in integrating the views and opinions of young people, parents and providers, it should be noted that the 'user' members of the Delphi panel were young people and parents derived from a membership list of the

Children's Chronic Arthritis Association. Thus, similar to the Delphi method study conducted by Zebrack *et al.* (2004) discussed earlier, there is some potential for bias in terms representation in this Shaw *et al.* (2004a) study, as, again, a very specific population of young people and parents were targeted.

In their study, McCurdy *et al.* (2006) adopted a qualitative case study approach to explore the process of transition in transplant care. To do so, seventeen young people aged 19 to 24 who had experienced transition for their transplant care were engaged a series of focus groups. In addition, interviews were conducted with a range of health care professionals to gather contextual information about transition generally and evidence gathered from electronic documents was collated. The findings revealed five elements of the transition process, with young people's perspectives indicating they either believed their transfer to adult care to be a big change in their lives or to be something they were expected to do as a result of their age. However, discerning the findings from the two other sources of data, the health care professional interviews and the extracted documentary evidence, was problematic, as no explicit reference was paid to these data, aside from an indication that three additional themes were threaded throughout the five elements of transition previously referred to. In addition, it is also worth noting that the content analysis approach adopted, which used an editorial format (McCurdy *et al.*, 2006), may have limited the depth of meaning that was generated from people's narratives, as a descriptive rather than an interpretative account was afforded. Moreover, as the authors neglected to triangulate the sources of data in their case study, with no mention at all of the documentary evidence, they failed somewhat in their aim to explore their identified case, the process of transition, in all its reality and complexity.

In spite of the clarity afforded by the definition of a health care transition posited by Blum *et al.* (1993) and later consensus statement by the American Academy of Pediatrics (2002), there is still some ambiguity in the application of these definitions within the literature. For example, the terms 'transition' and 'transfer' are often used interchangeably, doing little to positively flavour the discourse surrounding health care transitions for young adults living with chronic childhood onset conditions. For

example, reporting on their study of patient and parent views of transition in the context of cystic fibrosis, Boyle *et al.* (2001, p.435) state that "an opportunity for patients to meet and interact with the adult care team *prior* [original emphasis] to transition must be provided." However, as noted earlier, transition is a process, implying a sense of movement and development (American Academy of Pediatrics *et al.*, 2002; Chick and Meleis, 1989), thus the kind of introduction Boyle and his colleagues (2001) refer to here should take place as part of a planned transition process. This process is distinct to the act of transfer, which is what Boyle *et al.* (2001) imply in the above quote. In all actuality, transfer is considered to be a one-off event, and may be rarely anticipated (Sawyer *et al.*, 1997; Robertson *et al.*, 2006; Brooks *et al.*, 2009). Certainly, referring to the process of transition as transfer is misleading, as this implies a single act and completely negates the longevity that should surround the transition process (McDonagh, 2005). The ramifications of the misinterpretation and inappropriate application of terminology in this way not only impacts on the clinical rhetoric surrounding the concept of transition, but also, more importantly, on patients' discourse, in terms of generating an understanding of what the process means from their perspective (Kennedy *et al.*, 2007). So, whilst professional bodies such as the American Academy of Pediatrics (2002) advocate for a process to be implemented whereby young people are prepared, informed and ready for the move to the adult sector, there is a need to understand the reality of this from an experiential perspective. Moreover, given transition is known not only to be an issue for young people, there is a need to consider multifarious experiential perspectives of this process.

There is a paucity of studies, however, that have done this to date. Whilst some of the previously cited studies in this chapter have considered the experiences of young people and their parents (Boyle *et al.*, 2001; Casillas *et al.*, 2010), it is much rarer for studies to consider the experiences of young people and health care professionals (Hauser and Dorn, 1999). Fewer still studies have sought to provide an experiential understanding of the process of transition from a triadic perspective, that of young people, parents and health care professionals. Transition research of this nature is especially missing within a cancer context.

To summarise then, one can conclude that people's experiences of transition tend to have been explored retrospectively, but understandings of such experiences are typically limited by significant gaps between the point of transfer and participation in such studies. Whilst such gaps could, in part, be attributed to the longevity which surrounds the process of transition, experiential accounts which are captured much closer to the time of the transition process and the transfer event should be sought. Further, including young people and parents is important in transition research, particularly as it has been revealed that these groups can have particular expectations, similar and unique, of the process of transition (Boyle *et al.*, 2001).

3.5 Models of transitional care

As discussion throughout section 3.4 of this chapter revealed, consideration of experiential perspectives of transition and current transitional care provision are important, particularly in light of the increasing recognition that models of transition should move beyond being service-driven, to a position which honours a lifespan approach (Stewart, 2009). At this stage, however, very little evidence exists to suggest which model is most preferable. For example, evidence is lacking to suggest which model is the most appropriate in terms of ensuring patient satisfaction, cost effectiveness and patient-associated outcomes (While *et al.*, 2004; McDonagh, 2005), whilst previously, few papers actually discuss the efficacy of transition service models (Betz, 1998). Moreover, there is a paucity of papers which explore the impact of these models in terms of their ability to effectively or adequately meet the physical, social and psychological needs of young people during the transitional care period (While *et al.*, 2004). These latter issues are considered to be important in light of the process of transition of moving from paediatric and adult-orientated services being heralded as a developmental process (Betz, 1998). To clarify, the transition process should, Betz (1998) has argued, begin in childhood within the context of a lifespan perspective. Yet, it is rare for developed models to be evaluated or tested, especially so within a lifespan perspective, thereby limiting definitive claims that can be made about which approach provides the best outcomes for the young person and their family during the process of transition (McDonagh, 2007).

Thus, in light of the focus of the current study, it is appropriate to consider developed models of transition in a binary manner. Firstly, taking into account the experiential focus prioritised in this study, there is a need to consider ways in which patient experience has informed the development of models of transitional care. Secondly, since transition is typically likened to a developmental process, there is a need to consider models of transition in terms of their affinity to the developmental needs of young people and parents. It is argued that this approach to the following critique lends itself well to allow consideration of the extent to which the models developed thus far are able to meet the multi-dimensional needs of young people and their families during the process of transition from paediatric to adult care.

3.5.1 Critique of models of transitional care

As previously stated, two important, but hitherto unexplored areas ripe for a critique of models exist: experiential influences on the development of these models; and the affinity the models have with the developmental needs of young people and their families. In light of the current study's focus on survivors of childhood cancer, the following critique will draw on literature pertaining to models of transition specific to this field, in addition to literature in which models of transition are discussed in a broader illness context.

First, in a cancer context, in terms of models of transitional care, to date, the majority of literature which has considered transition as a priority issue has tended to do so alongside discussions of the provision of appropriate long-term follow-up care for survivors of childhood cancer (Harvey *et al.*, 1999; Friedman *et al.*, 2006; Eshelman-Kent *et al.*, 2009; Bashore, 2011; Eshelman-Kent *et al.*, 2011; Kenney *et al.*, 2011). The rareness of experiential accounts in which issues associated with transition have been explored, from the perspectives of young adult survivors of childhood cancer, their families and health care professionals, means very little empirical evidence surrounding the transition experiences of this population actually exists (Oeffinger *et al.*, 2000; Zebrack *et al.*, 2004; Casillas *et al.*, 2010). Consequently, much of the literature associated with transition to date in this field has tended to be service

provision, expert opinion, consensus, or commentary in nature (Konsler and Jones, 1993; MacLean *et al.*, 1996; Oeffinger *et al.*, 1998; Harvey *et al.*, 1999; Hobbie and Ogle, 2001; Rosen *et al.*, 2003; Viner, 2003; Hudson, 2005; Aziz *et al.*, 2006; Freyer and Kibrick-Lazear, 2006; Friedman *et al.*, 2006; Ginsberg *et al.*, 2006; Skinner *et al.*, 2007; Freyer and Brugieres, 2008; Eshelman-Kent *et al.*, 2009; Bashore, 2011).

In spite of this lack of experiential consideration, a number of models of transitional care have been posited. For example, four models were previously proposed by a consortium group in the USA and were defined as being disease-specific, generic, primary care or single-site in nature (Conference Proceedings, 1995). The models listed here were defined by conference participants (Conference Proceedings, 1995) at the international invitational conference *"Moving on: Transition from pediatric to adult care"* in the USA in the early 1990s (Blum, 1995). Whilst explicit reference was made to conference participants being those who work in areas of adolescent and young adult health care and with that population (Blum, 1995), no comparable statement relating to the attendance and participation of young adults and/or their parents at this conference was discernible.

Whilst the original discussion of these models was not specific to a cancer context, Hobbie and Ogle (2001) did later consider these specifically within the context of childhood cancer survivorship, but with little consideration of these models from a patient experience perspective. However, the extent to which the aforementioned models were derived from patient experience is debatable, as organisational elements appear instead to have dictated their construction. Similarly, organisational influences in the development of models of transition are also noted in later discussion by Friedman *et al.* (2006) in their discussion of a number of models of transition alongside models of delivery for follow-up programmes for survivors of childhood cancer. Their organisational, rather than experiential, influences are noted in their discussion of cancer centre-based models, community-based models, and combined cancer centre- and community-based models (Friedman *et al.*, 2006).

In contrast, however, an experiential perspective was prioritised in a study conducted by Gibson *et al.* (2005b), which sought to provide evidence to support the delivery of alternative models of long-term follow-up care for survivors of childhood cancer. The value of adopting this experiential-based approach was evident in the findings, as it was demonstrated that young people expressed strong preferences to see a specialist doctor for their long-term follow-up care, rather than a nurse or general practitioner. In addition, face-to-face consultations were preferred over alternative models, such as telephone or questionnaire-based methods of follow-up (Gibson *et al.*, 2005b). The authors conclude that findings such as these are important as they demonstrate the differences in young people's preferences for long-term follow-up, and from this study's perspective, consequently, transition, compared to recommendations advocated by health care professionals such as those proposed in the Scottish Intercollegiate Guideline Network document *Long term follow up for survivors of childhood cancer* (2004), discussed previously in Chapter 2, section 2.6.2. The findings from Gibson and colleagues (2005b), coupled with the rarity with which the experiences of young adult survivors of childhood cancer have actually been explored within a long-term follow-up and transitional care context, further highlight the need for a study such as the one explicated in this thesis.

It is, however, worth noting that a number of parallels do exist between the models outlined by Hobbie and Ogle (2001) and Friedman *et al.* (2006). First, the basis of the disease-specific model, for example, is that individuals move from a paediatric specialist team to a transition team that consists of paediatric and adult specialists, before then moving on to an adult provider system (Hobbie and Ogle, 2001). This, like the optimal cancer centre-based model survivorship clinic raised by Friedman *et al.* (2006), would involve a dedicated team of experts who provide continuity of care throughout all stages of the young person's experience, from active treatment to follow-up, then a transition from paediatric to adult care and eventually from the cancer centre to the community. The disease-specific model has been posited as one of the most commonly adopted when establishing long-term follow-up programmes for survivors of childhood cancer (Harvey *et al.*, 1999; Hobbie and Ogle, 2001), yet the

evidence base surrounding both its development and outcomes for young people and families, in terms of addressing those simultaneous life transitions, is scant.

In the primary-care model, the family physician or general practitioner is used as the care-coordinator (Conference Proceedings, 1995). This means, like with the community-based and combined cancer centre and community models (Friedman *et al.*, 2006), there would be some coordination between the 'risk-adapted follow-up' that the young person requires, and general primary care. Primary care, Friedman *et al.* (2006) suggest, is important for promoting independence on the part of both the survivor and their families. However, there is a dearth of evidence to suggest this is the case and the ways in which patient experience informs the risk-adapted follow-up young people require. There is a suggestion, however, that only those young people at minimum risk of developing clinically significant late effects are followed up exclusively in the community (Friedman *et al.*, 2006). Evidence to indicate that this kind of model of transitional care ensures the developmental needs of this population are met is also lacking.

The developmental needs of young people do however, appear better acknowledged in the generic model of transitional care (Conference Proceedings, 1995) as there is a suggestion that it is more adolescent-focused, in that the young person moves from paediatric to adolescent to adult health care services. Although this model seems similar in some ways to the disease-specific model discussed previously, in the generic model, care is instead coordinated by adolescent specialists and primary care, rather than the disease specialists. The role of the disease specialists shifts, from coordinators of the care to members of the team. Yet again though, the organisational components and structures influencing the development of this model are notable, as chronological staging, rather than individual experiences, appear to dictate movement between the different components of the care system. To demonstrate, the basis of generic models involve a young person moving from paediatric to adult care at age 14, to adolescent care for the period 15-24 years of age, then finally onto adult health care services at over 24 years of age (Conference Proceedings, 1995). Whilst an adolescent-focused approach, which should prioritise the developmental needs of young people

and their families, is implied through this model, an individual, patient-centred approach appears not to be.

The fourth transitional care model proposed was that of a single-site model, whereby the same clinical environment is used as the young person ages (Conference Proceedings, 1995). That is, rather than moving to different health care systems, the young person moves from paediatric to adolescent to adult care within the same health care system. This means many of the clinical services such as nurses, psychologists and social worker remain the same, but there is change in the primary care provider as the young person matures (Conference Proceedings, 1995). Like the disease-specific model, the single-site model has been considered previously to be one of the most frequent in terms of establishing long-term follow-up programmes for survivors of childhood cancer (Harvey *et al.*, 1999; Hobbie and Ogle, 2001).

Inherent within the models discussed thus far is a sense that the optimal approach to transition is one that is multidisciplinary in nature and one in which continuity of care is assured. These principles are also reflected in the call for a model of care across the cancer continuum by Hudson (2005). In light of the risk for adverse effects of cancer treatment and the impact of these on many aspects of a young person's future health and well-being, the model of care across the cancer continuum posited in the USA advocates for the use of primary intervention measures from the point of diagnosis, shifting to secondary prevention measures when long-term survival is achieved (Hudson, 2005). This model also recognises that a transition from paediatric to adult health care settings will be required, as survivors of childhood cancer complete their growth and development. Scant reference is, however, paid to how the model facilitates these associated developmental elements. Instead, there is concern that a model of transition which advocates for the transition of long-term survivors of childhood cancer from oncology to primary care settings is problematic due to the unease of primary care providers managing the medical care of survivors of childhood cancer (Hudson, 2005). Thus, it can be concluded that this model prioritises the clinical components of long-term follow-up care, not experiential or developmental components. Implications associated with reducing cancer-related morbidity are

highlighted in this model, rather than the impact it may have on patients' individual experiences of the process of transition and long-term follow-up care.

Evidence within this critique so far illustrates ways in which patient perspectives and experiences tend to be somewhat neglected in current models of transitional care, both in terms of their development and consideration of how they can meet individuals' needs. Further, the empirical evidence base surrounding the generation of these models is scant. As a result, the models tend to be based on organisational structures and clinical consensus, and tend not to have been evaluated. An absence of evaluative evidence is supported by a recent systematic literature review which was unable to identify any controlled studies that evaluated methods of long-term follow-up for survivors of childhood cancer (Heirs *et al.*, 2010).

However, more recently in England, there has been a move towards addressing some of the issues highlighted previously with the publication of the document, *Models of care to achieve better outcomes for children and young people living with and beyond cancer* (NHS Improvement, 2011) as part of The National Cancer Survivorship Initiative. Developed in collaboration with young adult survivors of childhood cancer, the views and experiences of children and young people are embedded in the four posited models of care, meaning their experiences can inform future care provision for this population (NHS Improvement, 2011). Varying from a traditional Principal Treatment Centre (PTC) clinician-led aftercare model, to a shared care mode including secondary and primary care, to a nurse-led model, with telephone and postal follow-up, to a supported self-management model (NHS Improvement, 2011), these models have recently undergone a period of testing in ten test sites across England. Whilst no one model has been specific to transition, the testing of the four models has led to a number of emergent principles for the provision of care for young adult survivors of cancer, one of which is the importance of a pre-planned, co-ordinated approach to transition for young people and parents, at all stages of this process (NHS Improvement, 2011).

Such developments are welcome, particularly in light of previous work, within a broader context of transition, which has sought to identify evidence for models of continuity in a transitional care context (Forbes *et al.*, 2002). A large-scale systematic literature review aimed to provide the first steps towards providing better transitional care management for young people with a chronic illness or disability (Forbes *et al.*, 2002). Multi-method in nature, the review focused specifically on good practices that address continuity during transition from child to adult services.

In their attempts to identify a broader range of practices, five separate tracer conditions in which continuity of care was deemed particularly important (Forbes *et al.*, 2002), were subjected to specific searches within the second search stream of the review. Consequently, searches for congenital heart disease, learning disabilities, cystic fibrosis, diabetes mellitus and muscular dystrophy were conducted. Although the authors justified the inclusion of these conditions on the grounds of their prevalence in childhood and the extent to which they transcend the spectrum of health service provision (Forbes *et al.*, 2002), other conditions, including childhood cancer, would have also met such criteria and were not included. Moreover, the conditions included in the review were selected as they were deemed easy to define and were amenable to improvement, but again these criteria would have held for childhood cancer, yet this illness was neglected entirely within the boundaries of the review parameters. In the context of the current study, therefore, exclusion of childhood cancer as a tracer condition is regarded as a limitation of the Forbes *et al.* (2002) review, particularly as it can be argued that survivors of childhood cancer do transcend the spectrum of health service provision, as many young people may require multidisciplinary input into their care, especially during the period of survivorship, which is recognised as the longest part of their overall cancer experience (Nathan *et al.*, 2011).

However, by manner of their synthesis of the evidence, Forbes and his colleagues (2002) were able to identify a number of domains of continuity that reflect the primary focus of good practice for both the young person and their family, during the transition from child to adult care. Four models of continuity in transition were derived from

their synthesis and proposed for testing: direct, sequential, professional and developmental (Forbes *et al.*, 2002; While *et al.*, 2004). However, the models varied in the degree to which they accounted for or honoured young people's personal growth and development (NHS Service Delivery and Organisation R & D Programme, 2002) and were limited by the weak evidence base available which informed their development (Forbes *et al.*, 2002). Notably, in terms of item type in the included literature which led to the conceptualisations of the aforementioned models, only 43 of the 126 appraised items were user accounts, with only five of these 43 papers rated strong in terms of the strength of evidence. So, not only were the included studies in this review characterised by limited methodologies, but they also typically had small and variable sample sizes, meaning the evidence collated was actually weak and inconclusive (Forbes *et al.*, 2002). Nonetheless, the conceptual models of transition that emerged from this review do still feature within current transition literature (Rapley and Davidson, 2010).

Despite its shortcomings in terms of evidence produced and conclusions drawn, the review by Forbes and others (2002) did reveal a real need to undertake work in which the experiences of transition of young people and their families are explored and understood. This aspect is particularly important in light of the minimal experiential information that informed the conceptualisations of the models of continuity in transition and as reflected in the minimal evidence base available to inform their development. In addition, in the context of the current study, again, the paucity with which survivors of childhood cancer are considered a population for whom issues of continuity and effective transition are important was particularly notable in the Forbes *et al.* (2002) review. As demonstrated previously in Chapter 2, section 2.6, the increasing numbers of children diagnosed with cancer who are surviving into adulthood necessitates understanding the experience of the process of transition for this population.

In that regard, although survivors of childhood cancer may be asymptomatic and in relatively good health during the process of transition and at the time of transfer, some individuals may have limited or poor knowledge of their illness history and the

risk of long-term late effects as a result of their illness (Nathan *et al.*, 2011). For those reasons, for survivors of childhood cancer, it is advocated that the transition process should encompass the provision of essential information about their illness history, including treatments (Hobbie and Ogle, 2001), before actually transferring to the adult health care system. Given the period of survivorship is often considered the longest part of the overall cancer experience for survivors of childhood cancer (Nathan *et al.* 2011), specific transitional experiences of this population should therefore be explored to increase our understanding of this phenomenon for these individuals.

To summarise, whilst a number of models of transitional care have been identified, these tend to be characterised by a number of limitations. Firstly, current models are drawn from a weak and limited empirical base, as illustrated both in the context of models within a cancer care context and highlighted in discussions of the conceptual models posited by Forbes and his colleagues (2002). Moreover, the empirical base is particularly restricted in terms of experiential evidence, as it rare to discern the extent to which patients' and families' experiences of the process of transition have directed and influenced the development of these models. Secondly, the extent to which the developmental needs of young people and their families are recognised and supported within current models of transitional care is variable. Some models, like the developmental model, for example (Forbes *et al.*, 2002), recognise and actively focus on the personal growth of the young person and their family during transition. Although this model is considered to redefine the role of the family in the provision of care parallel to the development of the young person, the validity of this model, like the others discussed previously in this chapter, cannot be assured due to the limited body of experiential evidence considered in the development of the model.

3.6 Chapter Summary

This chapter has considered the way in which the process of transition between paediatric and adult health care services is defined and characterised. Key principles of health care transition have been deliberated by reflecting on ways in which these principles have been informed from empirical evidence and the extent to which these

are supported or refuted from experiential perspectives in both current literature and policy and practice documentation. In addition, in light of the experiential focus of this study and the developmental perspectives associated to a health care transition, an opportunity was also afforded in this chapter to critique a number of models of transition from this dual perspective. This critique revealed that not only are such models drawn from a weak and limited empirical base, but there is also a distinct lack of experiential research of the process of transition in a cancer context. In particular, there is somewhat of a limited evidence base in terms of research which is methodologically robust, allows for an exploration of the actual experiences of young people and their families, and considers the multi-dimensional nature of the experience of the process of transition. Chapter 4 will therefore explicate ways in which this study sought to address this gap by outlining the methodological approach adopted in the current study.

Chapter 4 Methodology

4.1 Introduction

In Chapter 3, the critical discussion of the literature highlighted the paucity of transitional care research which is methodologically and theoretically informed. Indeed, much previous transition research has commonly neglected to specify, or even identify, the epistemological position from which the authors have drawn to inform their work, opting instead to locate their work within the broad quantitative and qualitative methodological paradigms. In so doing, many previous authors fail to contextualise their work in terms of offering possible underlying assumptions, particularly those authors who have sought to explore people's experiences of transitional care. In addition, previous transition research has all too often failed to draw on a theoretical framework to provide contextual understandings of people's experiences.

As identified in Chapters 2 and 3 previously, the experiences of survivors of childhood cancer of transitional care have rarely been prioritised. Although many governmental agencies recognise the importance of identifying and understanding health care experiences from patients' perspectives (Scottish Government, 2008; Scottish Government, 2009a; Scottish Government, 2009b; National Institute for Health and Clinical Excellence, 2012), with the process of transition from paediatric to adult care one such viable experience, it is believed that a greater emphasis on these experiences is still required to ensure real improvements in care (National Institute for Health and Clinical Excellence, 2012). Indeed, the importance of identifying and understanding patients' experiences of health care have been further highlighted in a recent literature review which sought to conceptualise the experience of health care delivery (Entwistle *et al.*, 2012). The conceptual contributions from this review have positively flavoured the evidence base surrounding our understandings of patient experiences within a health care context, particularly as the review identified a variety of experiences associated with health care delivery that have significance for and to patients (Entwistle *et al.*, 2012). Thus, as introduced in Chapter 1, and reiterated

throughout Chapters 2 and 3 previously, experiences are very much the driver for the current study. In this regard, the current study was developed in recognition of the real need to adopt careful and context-specific explorations of people's experiences within practice (Entwistle, 2009).

However, in addition to reiterating the ways in which experiences have provided the driver for the current study, it is also important to disclose the traditions that informed this work, as transparent explication of ontological and epistemological assumptions are essential to develop an understanding of the interrelationship of the key components of research (Grix, 2010). Therefore, the current chapter will seek to explore and extrapolate the philosophical basis on which this researcher has drawn, consequently informing the approach to the current study.

Denzin and Lincoln describe qualitative research as "multi-method in focus, involving an interpretative, naturalistic approach to its subject matter" (1998:3) and it is on such a definition this researcher draws. A qualitative approach was considered the most appropriate for the current study in light of its focus on and prioritisation of people's experiences, as highlighted previously and in earlier chapters. Furthermore, a qualitative, rather than quantitative approach, was considered the most appropriate as it would allow a detailed perspective on the topic to be presented (Creswell, 1998). Indeed, the experience of the process of transition from paediatric to adult cancer services was considered to be particularly ripe for qualitative exploration, given the paucity of understanding of this across the literature, as identified in Chapters 2 and 3 previously. Thus, it was decided that the current study would be best situated within the qualitative paradigm, with the power of this positioning, particularly in terms of data generation, emphasized by Patton (2002):

> *Qualitative data describe. They take us, as readers, into the time and place of the observation so we know what it was like to have been there. They capture and communicate someone else's experience of the world in his or her own words. Qualitative data tell a story.* (Patton, 2002, p.47)

Therefore, the discussion that follows will rationalise the decision to locate this study within the qualitative paradigm and will critique epistemological and methodological frameworks traditionally located therewith. However, this researcher, like Denzin and Lincoln (1998), refers to these methodological frameworks as strategies of inquiry throughout. First, however, section 4.2 will discuss the philosophical background to the project and, in so doing, will provide the backdrop to argue for a case study based approach as the most appropriate research strategy for this research study.

4.2 Philosophical orientation

Denzin and Lincoln (1998) have argued that qualitative research can be difficult to fit into a simple definition because a range of disparate theoretical and epistemological paradigms can each legitimately lay claim to the effective use of qualitative research strategies and methods. However, by being clear about their epistemological and methodological commitments, researchers can make clear decisions about which methods can be used (Willig, 2001). Thus, qualitative research requires researchers to consider the various methodologies and epistemologies, often referred to as paradigms, which can inform and guide the approach to their inquiry of choice (Guba and Lincoln, 1994). A paradigm is the belief system which guides the researcher ontologically, epistemologically and towards their choice of methods (Guba and Lincoln, 1994). According to Grix (2010), these elements exist in an interwoven and dependent fashion:

> *By setting out clearly the interrelationship between what a researcher thinks can be researched (her ontological position), linking it to what we can know about it (her epistemological position) and how to go about acquiring it (her methodological approach), you can begin to comprehend the impact your ontological position can have on what and how you decide to study.*
> (Grix, 2010, p.67)

Ontology, then, addresses the nature of the world, the nature of reality for researchers and what their beliefs are about what there is to know about the world (Creswell,

1998; Willig, 2001; Snape and Spencer, 2003). Ontological stances adopted by researchers may be described broadly as 'realist' or 'relativist' (Willig, 2001), although multiple subsidiary variances of both do exist. Realists, for example, maintain that the world consists of structures and objects that have a cause-effect relationship with one another, whereas relativists, by contrast, emphasize the diversity of interpretations that can be applied to a world which is not orderly in the way realists believe it to be (Willig, 2001).

Ontological stances are, however, intertwined with the epistemological paradigm of choice that guides inquiry, which, as revealed by Grix (2010) in the previous quote, are those stances which make it possible to know about the world. Denzin and Lincoln (1998) identified four primary interpretative paradigms which represent the researcher's ontological, epistemological and methodological premises and which afford some structure to qualitative research, thereby placing particular demands on the researcher (Denzin and Lincoln, 1998). They further identify four major paradigms: positivist and post-positivist; constructivist-interpretive; critical; and feminist-poststructural.

Having introduced the notion of epistemology and ontology and their influence on researchers and their choice of inquiry, it is timely for the foundations underpinning the current thesis to be explicated. Such foundations are revealed in section 4.2.1 that follows.

4.2.1 Philosophical orientation: Constructivist-interpretive paradigm

The constructivist-interpretive paradigm, in which it is recognised that people experience the world according to a complicated mixture of social and contextual influences rather than in purely objective or direct forms (Moses and Knutsen, 2007), provides the assumptions which underlie and inform key components of the current research, including the research questions, methodology and methods (Grix, 2010). Constructivists are concerned both with the multiple realities constructed by people

and what the implications of these constructions are for people's lives and their interactions with others (Patton, 2002; Galvin, 2005).

The ontological basis of a constructivist approach is relativism. Here, there is a recognition that multiple realities do exist, with these realities extending beyond those of the individuals being investigated to also those realities of the researcher and the realities of the reader who interprets a study (Creswell, 1998). Realities are recognised as being socially and experientially based (Guba and Lincoln, 1994), with an emphasis by relativists on the diversity of interpretations that can be applied to the world (Willig, 2001).

In terms of epistemological positioning, constructivists-interpretivists adopt a subjectivist stance (Denzin and Lincoln, 1998). The investigator and the respondents are considered to be interactively linked, meaning the "findings are *literally created* as the investigation proceeds" (Guba and Lincoln, 1994, p.111) [original emphasis], with the nature of these social constructions elicited and refined through the interaction between the investigator and the respondents through the use of a naturalistic set of methodological procedures (Guba and Lincoln, 1994; Denzin and Lincoln, 1998). Further, within interpretivism, the social world can be explored and understood through the participants' and the researchers' perspectives and understandings (Snape and Spencer, 2003). Within such a paradigm, the interactions between the investigator and the subjects of the investigation are a key defining feature, with such interactions permitting a co-construction of findings through the interactive dialogues between the two parties (Ponterotto, 2005). Interpretation is essential within this perspective if there is to be some movement beyond the data (Rapport, 2005) to generate explanations about why people do or think as they do (Gerring, 2007).

For this researcher, the constructivist-interpretive positioning, in which the relationship between the researcher and the participant is emphasized, and the ways in which these individuals contribute to the co-construction of meaning (Mills *et al.*, 2006b), is the most appropriate epistemological view for this thesis. This stance is particularly suitable in light of the foundations of other potential paradigms she

confidently rejected in identifying her ontological and epistemological positioning within the context of the current study. The rationale for rejecting these other potential paradigms is explicated in section 4.2.2 that follows.

4.2.2 Possible philosophical positions

Drawing again on the terminological positioning of Denzin and Lincoln (1998), all three remaining paradigms posited by these authors – positivist and post-positivist, critical and feminist-poststructural – were rejected within the context of the current study in light of the assumptions made by constructivist-interpretive theories and their applicability to the current study. To demonstrate, within the constructivist-interpretive paradigm there is a belief that in order to understand the world of lived experience and meaning, one must interpret it (Schwandt, 1998).

In contrast, the positivist perspectives, which primarily refer to the "received view" (Guba and Lincoln, 1994, p.202) of science, tend to focus on the verification or falsification of a priori hypotheses, and seek "to discover and explain patterns that are assumed to exist in nature" (Moses and Knutsen, 2007, p.8). Ontologically, there is a belief that the world is constructed by structures and objects that have a cause-effect relationship to one another (Willig, 2001), with the investigator and the investigated "object" assumed to be independent entities in epistemological terms (Guba and Lincoln, 1994, p.204). However, this researcher rejects this notion of the singularity of human knowledge in the context of the current study, as instead the notion that the world is socially constructed as a result of the interactions of individuals (Grix, 2010) is more appropriate. The purpose of inquiry in this paradigm also buffers against this researcher's epistemological positioning in the context of this study, as positivist research seeks explanations to allow the prediction and control of physical or human phenomena (Guba and Lincoln, 1994; Grix, 2010), whereas for this research, understanding that the meaning of a social action is important from both the perspective of the person performing it and the researcher studying it (Moses and Knutsen, 2007) is appropriate.

Continuing with the terms outlined by Denzin and Lincoln (1998), the two further paradigms outlined by these authors, those of critical and feminist-poststructural, were also rejected, as this researcher struggled to identify with their ontological and epistemological foundations in the context of the current study. In ontological terms, a materialist-realist ontology tends to be employed in both critical and feminist approaches, meaning an external reality is considered to exist independent of our beliefs or understanding, as only the material or physical world is considered 'real' (Snape and Spencer, 2003). It is the real world that is considered to make a material difference, with the empirical materials collected and theoretical arguments developed evaluated against a backdrop of emancipatory implications (Denzin and Lincoln, 1998). Although realism, particularly so critical realism, is considered to overlap positivist and constructivist-interpretive paradigms (Moses and Knutsen, 2007; Grix, 2010), its ontological core is closest to that of the positivist positions, in that it recognises that a real world exists, independent of our experience (Moses and Knutsen, 2007; Grix, 2010). Despite this stance, there is a belief within critical-realism that there may be multiple layers to the reality that such researchers wish to study, thus there is a need to move from causal explanations to a more interpretative understanding, although there is never a full departure from positivist underpinnings (Grix, 2010; Moses and Knutsen, 2007). Although receptive of the fusion between ontology and epistemology in this paradigm, this researcher was more critical of its insistence that what can be known "is inextricably intertwined with the interaction between a *particular* investigator and a *particular* object or group" (Guba and Lincoln, 1994, p.206) [original emphasis], particularly as there is some belief that the explanations that critical-realists offer are dependent on the identification of causal mechanisms, which must be both efficient and material in nature (Grix, 2010).

In summary then, a positivist epistemological stance was not suitable or appropriate as a guiding framework for this study, nor was a realist ontological stance. Rather, a stance which would better reflect the qualitative nature of inquiry of this study and the positioning of the researcher in the context of this study was instead advocated. As such, a constructivist-interpretive stance was adopted, as illustrated previously in section 4.2.1, with the research strategy and associated methods adopted in the

current study congruent with this philosophical positioning. By explicating her positioning in this study in this way, the researcher has provided a suitable milieu for the next section, in which the justification for the adoption of a case study approach shall be outlined. This delineation will be apparent both within the context of this researchers epistemological positioning in the context of this thesis and in light of the other three major strategies of interpretative inquiry qualitative researchers may use; phenomenological, ethnographic and grounded theory techniques (Creswell, 1998; Denzin and Lincoln, 1998).

4.3 Strategies of inquiry

Section 4.2 highlighted the importance of situating research within a particular epistemological paradigm. Doing so, Holloway and Todres (2005) argue, provides the researcher with greater clarity on the topic of research, the questions to be asked, the ways in which research questions are answered and communication of the findings from the work. Further, the actual strategy of inquiry will characterise how the phenomenon of interest will be studied (Silverman, 2005), but to ensure an appropriate strategy of inquiry or a methodological approach is adopted, the philosophical underpinnings of said strategy of inquiry or methodology must be compatible with the epistemological position of the researcher. Therefore, drawing on a constructivist-interpretive epistemology prohibits this researcher's adoption of some approaches, but permits others to answer the research question posited in this thesis.

4.3.1 Phenomenology

A common strategy of qualitative inquiry is phenomenology. Phenomenology seeks to provide relevant and transferable insights into what an experience is like by describing, interpreting and understanding its meanings (Holloway and Todres, 2005). Indeed, phenomenologists strive for close and detailed examinations of individual experiences, and seek to unearth a deeper understanding of these lived experiences by "exposing taken-for-granted assumptions about these ways of knowing" (Starks and Brown Trinidad, 2007, p. 1373).

Derived from key scholars such as Edmund Husserl (1962), Martin Heidegger (1962) and Hans-Georg Gadamer (1989), phenomenology and hermeneutic phenomenology, as developed by Heidegger and Gadamer, is concerned with the life world and human lived experiences (Laverty, 2003). Ontologically and epistemologically, the two strands of phenomenology are considered to differ, as Husserl's approach to phenomenology emphasizes epistemological questions of knowing, thereby focusing on experience, whereas Heidegger's hermeneutic approach is more concerned with the experience of understanding, so those existential-ontological questions (Koch, 1995). So, too, do the approaches differ in terms of the extent to which the world is 'bracketed' in the context of the research (Yanow, 2005). Husserl, for example, was a proponent of the notion that the researcher should set aside or suspend any of his or her biases, presuppositions or existing knowledge of the phenomenon to ensure that an understanding of the phenomenon is generated entirely through a participant's descriptions of their experiences of the particular phenomenon (Husserl, 1962), whereas Heidegger denounced such an approach, believing a presuppositionless perspective impossible (Heidegger, 1962). Moreover, whilst Husserl's approach focused more on the relationship between the person and the object of study, Heidegger was more concerned with the nature of reality and being in the world (Laverty, 2003). Also, as phenomenological research is regarded as being descriptive in nature, there is a particular focus on the structure of an experience, whereas hermeneutic phenomenology is considered to be more interpretative and instead focuses on the historical meanings of experience (Laverty, 2003). Meaning here, it is said, is considered to arise from "interpretative interaction between historically produced texts and the reader" (Laverty, 2003, p.16). Further, differences between the two strands of phenomenology are noted in terms of the ways in which findings are generated and in how findings are used (Lopez and Willis, 2004). For example, descriptive phenomenologists seek descriptive categories of the real and perceived worlds of their participants (Lopez and Willis, 2004), whereas those phenomenologists ascribing to hermeneutic traditions will focus on describing the meanings of their participants' being in the world, and how such meanings influence choices they make (Lopez and Willis, 2004).

Whilst phenomenological approaches can offer a sophisticated and detailed description of people's experiences by exposing taken-for-granted assumptions about ways of knowing (Starks and Brown Trinidad, 2007), and although the notion of the impossibility of bracketing heralded within a hermeneutic phenomenological approach did resonate with the researcher, the dismissal of the co-construction of meanings in this context is an important critique of this strategy of inquiry in the context of the current thesis. In phenomenology, close attention is paid to individual experiences, with the truth of an event only knowable through "embodied perception" (Starks and Brown Trinidad, 2007, p.1374), meaning there is limited acknowledgement of the multiple realities so favoured within the constructivist-interpretive paradigm. Therefore, as the current study is indeed concerned with multiple realities, not only those of the young people, but also those of their friends or family members and from a health care perspective, in addition to the realities of the researcher, a phenomenological approach was discounted as it is important that these multiple realities were acknowledged in order to allow the posited research question to be answered.

4.3.2 Grounded Theory

Grounded theory, as originally developed by Glaser and Strauss in the 1960s, was posited as a method by which researchers could systematically generate theory grounded in empirical data (Glaser and Strauss, 1967). At the time, grounded theory was considered distinguishable from other qualitative methods as a result of its goal in generating theory in combination with the completeness of method it afforded (Walker and Myrick, 2006). In grounded theory research, data collection is considered inductive in nature, as the issues of importance to participants "emerge from the stories that they tell about an area of interest that they have in common with the researcher" (Mills *et al.*, 2006b, p.3). Adopting this stance assumes that the researcher is considered to have no particular ideas to prove or disprove within the context of the research, rather, that they engage in the process to generate theory from the data (Walker and Myrick, 2006). As such, research questions in grounded theory research are framed in such a way as to allow researchers to inquire about the ways in which

social structures and processes influence how particular things are achieved, within the context of a given set of social interactions (Starks and Brown Trinidad, 2007). The goal, therefore, is to develop theories which are both plausible and useful, informed by interactions of people, actual events and people's interactions with each other (Holloway and Todres, 2005), and are thus able to explain basic social processes (Strauss and Corbin, 1998; Starks and Brown Trinidad, 2007). However, to allow the generation of these theories, purists would suggest the researcher begins a study without a preconceived idea of the theory in mind or any prior knowledge of the literature and instead allows the theory to emerge from the data collected (Strauss and Corbin, 1998). Grounded theory assumes an objective external reality (Charmaz, 2003), but such assumptions were considered originally to be attributed to the positivist paradigm (Charmaz, 2003). Epistemologically, such a positioning is at odds with the positioning assumed by the researcher in the current study, thus this form of grounded theory was rejected in the current study as a strategy of inquiry due to the evident buffering against her epistemological positioning.

Grounded theory has, however, evolved somewhat from the early seminal works aforementioned. The tools associated with grounded theory have moved beyond such positivist underpinnings to a more open-ended approach, in which emergent constructivist elements are instead prioritised (Charmaz, 2000; Charmaz, 2003). Further, the nature of the relationship between the researcher and the participant differs somewhat in a constructivist approach to grounded theory, as here, the researcher is positioned as the author of a reconstruction of experience and meaning (Mills *et al.*, 2006b). Thus, unlike the aforementioned approach to grounded theory, Charmaz instead emphasizes the ways in which the researcher should be kept as close as possible to the participants throughout, and ensures that the participant's voice and meaning remain intact throughout the processes of analysis (Mills *et al.*, 2006b). As a result, Charmaz is an advocate for the use of creative writing to communicate the ways in which people construct their worlds (Mills *et al.*, 2006b).

Although some of the principles of this constructionist approach to grounded theory were regarded to have some semblance with this researcher in the context of this

thesis, because there are notable similarities with the epistemological stance adopted, the principal purpose of grounded theory, theory generation, did not marry with the aim of the current research study. Rather than focusing on evolving theory, this study was instead constructed with a view of an openness to discovery (Bluff, 2005), reflected in the interpretative approach adopted. Further, as research questions in grounded theory are established to permit the inductive distillation of issues of importance for particular groups of people (Mills *et al.*, 2006a), this contrasts to the research question posited in the current study, which was much more exploratory in nature as it sought to consider people's experiences. Thus, grounded theory was rejected as a potential methodological framework for the purposes of the current study.

4.3.3 Ethnography

A third interpretative strategy of inquiry considered in the context of the current research study was that of ethnography. Ethnography, an approach commonly found within social research, aims to "capture an all-inclusive understanding of the social and cultural world of people" (Sharkey and Aggergaard Larsen, 2005, p.169). The meaning of the term 'ethnography' can nonetheless vary, with considerable overlap with other qualitative approaches and their boundaries (Atkinson and Hammersley, 2007). Unlike the strategies of inquiry discussed previously in sections 4.3.1 and 4.3.2, there tends to be no consensus about the underpinning epistemology behind ethnography – it is argued that ethnographers will adopt different paradigmatic stances in this research, such as interpretive, positivist or humanist, depending on their own personal orientations (Sharkey and Aggergaard Larsen, 2005). This divergence may, in part, be a result of the wide variety of philosophical and theoretical ideas that have influenced ethnography, including symbolic interactionism, feminism and constructionism (Atkinson and Hammersley, 2007).

Whilst ethnography shares many characteristics of other strategies of qualitative inquiry within the interpretative paradigm, including observations of participants and the conduct of interviews to advance understanding of what is occurring within a

particular setting, ethnographers seek to specifically understand what participants do to create the culture in which they live and to understand how such a culture develops over time (Atkinson and Hammersley, 2007). Thus, participant observation, either overt or covert, is considered to be central to the method of ethnography (Sharkey and Aggergaard Larsen, 2005). Although ethnographic approaches are increasingly being used in health care contexts, particularly in terms of highlighting differences in access to health services (Sharkey and Aggergaard Larsen, 2005), the purpose of this study is not to understand the development of a culture in ways ethnographers would ascribe to. Rather, the purpose of the study is to explore a particular experience from a variety of perspectives, thus harnessing some of those principles that define ethnography, but within the context of an experiential exploration of a particular issue. As such, an ethnographic approach to the current study was rejected.

Having presented and discussed three main strategies of inquiry in the context of the qualitative and interpretative stance adopted in this study, alongside the justification for their rejection, discussion shall move to the fourth commonly regarded primary interpretative strategy of inquiry, and that which was actually employed in the current study, that of a case study approach. In section 4.4, the researcher will provide the justification and rationale for selecting a case study approach in light of the differing approaches to this strategy of inquiry and the opportunities this strategy affords to consider the multiple realities surrounding the experience of the process of transition from paediatric to adult cancer care in the context of the current study.

4.4 A case study approach

4.4.1 Rationale for a case study approach

Case studies are defined by the interest in an individual case (Stake, 2008) and are fundamentally undertaken to explore and understand the uniqueness and distinctiveness of said individual case (Simons, 2009). The particular case of interest can be a situation, experience or incident, a community, organisation or institution or an individual (Gillham, 2000; Willig, 2001). The strengths of a case study lie in its ability to provide explanations as to how and why things occur as they do within these

particular contexts by exploring multiple perspectives and examining any contested viewpoints that emerge (Simons, 2009).

A number of epistemological arguments underpin case study research. In terms of assumptions about the world, case studies take an idiographic approach, in that they focus upon the particular and they are able to provide detailed and careful descriptions of individual cases at the idiosyncratic level before cautious progression towards theory development or generalisation (Willig, 2001). Case study research can be said to resonate with the critical realist epistemological strand, as it is often considered to be based upon the assumption that patterns of experience or behaviour are never expressed in predictable or uniform ways and often views the world as an integrated system, with parts of the world impossible to be studied in isolation (Willig, 2001). This stance would appear to jar with the researchers philosophical orientation, but, in contrast, others, such as Stake (1995) and Yin (2009), would argue that case study research is much more aligned to the constructivist paradigm; a positioning that resonates with this researcher in the context of this thesis. Indeed, accepted strengths of the case study approach include its ability to provide explanations for how and why things occur as they do within particular contexts (Madill *et al.*, 2000), its adaptability (McDonnell *et al.*, 2000), and opportunities for the reader of a case study to gain experiential understandings of what is happening within a case through the researchers' interpretations and narratives (Stake, 1998). Certainly, in a qualitative case study, the researcher must adopt an ongoing interpretative role, to sophistically navigate through the thick descriptions and multiple realties so expected in qualitative case studies (Stake, 1994). The notion of these multiple realities and the desire to interpret these therefore marry well with the foundations of the constructivist-interpretive epistemological positioning adopted for the purposes of this thesis, as explicated previously in section 4.2.1. Such synergy and the rationale for the adoption of a case study approach are further reinforced in light of the epistemological foundations of other major strategies of qualitative inquiry, as revealed previously in section 4.3.

4.4.2 Defining case study research

How best to define case study research has long been the focus in much of the literature surrounding this research strategy. Ultimately, there is a level of consistency between various definitions, but some discrete differences should also be acknowledged. Previously, Orum and colleagues (1991) defined case study as:

> *… an in-depth, multifaceted investigation, using qualitative research methods, of a single social phenomenon. The study is conducted in great detail and often relies on the use of several data sources.* (Orum *et al.*, 1991, p.2)

This definition of case studies, Yin (2009) has argued, is too broad, thus a more technical definition is required in order to encapsulate both the scope of a case study and its associated technical characteristics, such as the strategies for data collection and analysis, as reflected in the following extract from Yin's (2009) extended definition of case studies:

> *The case study inquiry copes with the technically distinctive situation in which there will be many more variables of interest than data points, and as one result relies on multiple sources of evidence, with data needing to converge in a triangulating fashion …* (Yin, 2009, p.18)

Yet, a further definition of case studies has been posited by Yin's scholarly contemporary of the case study approach, Robert Stake, who places less emphasis on the theoretical elements of case study research in his definition than that of Yin. Rather, his focus is on the particularity and complexity that bounds a single case, with the aim of the case study to "understand its activity within important circumstances" (Stake 1995, p.xi). However, in recognition of the commonalities between definitions such as those aforementioned, particularly in terms of the commitment they each afford in terms of studying a situation in its 'real life' context (Simons, 2009), yet a further definition of case study should be considered. Incorporating a research focus and building on the definitions previously afforded by Yin (2009) and Stake (1995), Simons (2009) offers the following definition:

> *Case study is an in-depth exploration from multiple perspectives of the complexity and uniqueness of a particular project, policy, institution, programme or system in a 'real life' context. It is research-based, inclusive of different methods and is evidence-led. The primary purpose is to generate in-depth understanding of a specific topic (as in a thesis), programme, policy, institution or system to generate knowledge and/or inform policy development, professional practice and civil or community action.* (Simons, 2009, p.21)

Reviewing these definitions in this way has highlighted how there is some consensus surrounding the object of a case study, that of a temporally bound unit. However, also evident are the ways in which some methodological variances also flavour the discourse surrounding case studies, particularly so in terms of which methods may be used in the context of this strategy of inquiry. However, there is a sense within case study research that the use of particular or different methods can be justified, so long as their use contributes to the knowledge we generate about the case to be studied (Verschuren, 2003). The data collection methods used in case study research are considered in forthcoming section 4.5. First, however, it is important to consider different types of case study designs, as close examination of these influenced the ways in which the use of the case study as a strategy of inquiry was implemented in the context of the current study.

4.4.3 Types of case study

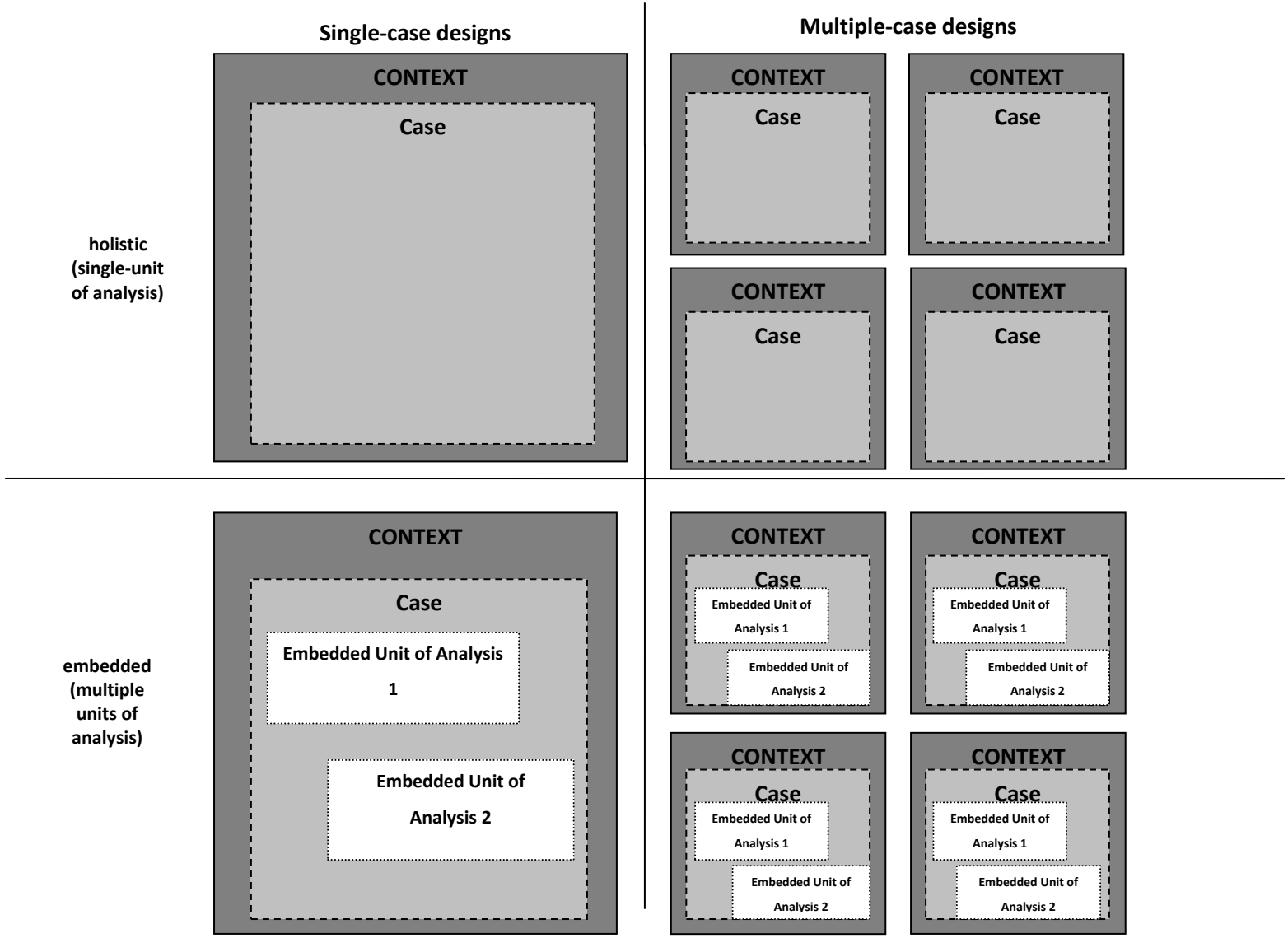
The type of case study to be conducted should be determined not only by the research question to be answered, but also by the way in which the boundaries of the case have been determined (Baxter and Jack, 2008). Thus, any decision will be influenced by the purpose of the study, which will, in turn, influence the selection of a specific case study design, which can vary from describing, exploring, or comparing between cases (Baxter and Jack, 2008). The two most prolific authors in this field, Robert Yin and Robert Stake, use different terms to describe and differentiate between various types of case studies.

For example, Yin (2009) categorises case studies as being explanatory, exploratory or descriptive in nature, and offers a further level of differentiation in terms of single, holistic, or multiple case studies (Baxter and Jack, 2008). For Yin (2009), four types of case study design are central to his discussions of types of case studies and case study research, as reflected in Figure 2 on page 112. Here, Yin (2009) argues, every type of design includes the need to analyse any contextual conditions in relation to each case. On the other hand, Stake (1995) argues that there are three distinguishable types of case study: intrinsic, instrumental, and collective. An intrinsic case study, he argues, would be conducted if researchers have a genuine interest in the case and wish a better understanding of that particular case, but the purpose is not to build theory (Stake, 1998; Baxter and Jack, 2008). An instrumental case study, on the other hand, is conducted to provide insight into a particular issue or refine theory, with an individual case examined in depth to allow its contexts to be scrutinised (Stake, 1998; Baxter and Jack, 2008). Similar to an instrumental case study, a collective case study would be conducted if the interest is on more than one case, that is, if the researcher may wish to study a number of cases simultaneously to inquire into the population or phenomenon of interest, thus it is an instrumental case study extended to several cases (Stake, 1998). However, despite their posited variations in types of case studies, Stake (1995) and Yin (2009) do concur on particular case study rationales, such as the use of multiple sources of evidence, the need for such studies to be set in real-life settings and the focus of a case study on a particular contemporary phenomenon (Walshe *et al.*, 2004). Nonetheless, their approaches to and conduct of case studies do vary, as intimated previously, and are further expanded below.

Firstly, Yin (2009) advocates that there are two fundamental decisions to be made within the context of case study research: a) adopt a single-case or multiple-case study, and b) adopt a holistic or embedded design. He argues that single-case studies can be advantageous, particularly for unique, rare or critical cases, but multiple-case studies allow for literal and theoretical replications to be explored (Yin, 2009). Further, he states that multiple-case studies are often preferred over single-case studies; single-case studies can become vulnerable due to the dependency placed on the single case, whereas analytically, multiple-case studies are considered to be stronger as

possibilities for direct and theoretical replication exist (Yin, 2009). Literal replications are those which produce similar results, whereas a theoretical replication can predict contrasting results, but for reasons which can be anticipated (Yin, 2009).

Figure 2: Yin's 2 x 2 case study design matrix



In contrast, Stake's approaches to case study research are more malleable. Whilst he coherently defines his three primary typologies, his approaches are not insistent upon the use of theoretical propositions or theory development (Walshe *et al.*, 2004); rather, in an intrinsic case study, for example, a case is studied as it is of some interest in its own right, rather than constituting a more general phenomenon or issue (Stake, 1995; Willig, 2001). Instrumental case studies, on the other hand, constitute exemplars of a more general phenomenon, and through their selection, provide the researcher with the opportunity to study the phenomenon of interest (Stake, 1995; Willig, 2001). Finally, Stake would argue that collective case studies are undertaken to form a collective understanding of a particular issue by selecting several cases to study (Stake, 1995), and are thus similar in many ways to an instrumental case study. However, unlike an instrumental case study, in which the focus is on one particular case, within a collective case study, a number of cases are studied simultaneously to inquire into the population, particular phenomenon, or the general condition (Stake, 1994).

Further differences are noted between the two scholars in terms of considering the units of analysis within a case study, as this, Yin (2009) would argue, can determine whether a case study is considered holistic or embedded in nature. Ultimately though, a design decision such as this rests upon the particular phenomenon being studied and the research questions constructed to explore it. For example, within a multiple-case study, a holistic design would be appropriate if data are collected for a range of organisations or programmes, but not pooled across these. Rather, the collected data form part of the findings generated for each individual organisation or programme – thus each individual case (Yin, 2009). In contrast, a multiple-case embedded design would instead be more appropriate if the purpose of the case study was to address the same issue at a number of sites, such as the implementation of a new operating procedure. In this situation, pooling the data and comparing these across sites would facilitate the exploration of literal and theoretical replications (Yin, 2009).

Stake (1995), however, argued that distinctions in terms of units of analysis are most vital in the context of selecting appropriate methods and sources of evidence for exploration within the realms of the particular case study design. In instrumental and

collective case studies, for example, individuals experiencing the chosen phenomenon represent suitable cases for analysis, as it is believed that an understanding of these cases will permit a better understanding, and potentially better theorising, of a larger still collection of cases (Stake, 1998; Willig, 2001).

One of the considered strengths of the case study approach is its ability to provide explanations for how and why things occur as they do within particular contexts (Madill *et al.*, 2000). Yet, types of case studies can be distinguished at a level beyond the typologies afforded thus far, as there are further discrete differences which bind types of case study. That is, case studies may be considered explanatory, descriptive or exploratory in nature. First, explanatory case studies are concerned with generating explanations for the occurrences to which they are associated (Willig, 2001), whereas descriptive case studies instead seek to provide a detailed description of the phenomenon of interest within its context in order to provide a better understanding of the nature of this phenomenon. Finally, those case studies considered exploratory in nature are those which seek to explain the particular phenomena of interest (Willig, 2001).

Indeed, such is the flexibility of case study research that various types of case studies have previously been conducted in health care contexts. For example, the case study approach has previously been considered appropriate for use in palliative care contexts, as it is has been argued that it offers, amongst other things, an appropriate framework to use when multiple perspectives are required and when complex situations need to be addressed (Walshe *et al.*, 2004). Similarly, Payne *et al*. (2007), discussed the benefits of adopting a case study methodology in areas of research such as end-of-life and bereavement care and, as raised previously in Chapter 3, McCurdy *et al.* (2006) utilised a case study approach to consider the transition process in transplant care. It is has been argued that an approach to research in which the case-study strategy is adopted can "contribute to the cumulative development of knowledge" (Flyvberg, 2006, p.241), and this has been well supported across the literature (Bergen and While, 2000; McDonnell *et al.*, 2000; Hewitt-Taylor, 2002; Walshe *et al.*, 2004; Payne *et al.*, 2007).

Thus, in summary, it appears that the flexible boundaries of case studies do offer considerable scope for exploration, particularly so as variable methods of data collection can be employed within this research strategy. Approaches to data collection and consideration of multiple perspectives are key features of case study research, and, as such, shall be considered in section 4.5 in the context of what makes a case study a case study. Following this discussion, section 4.6 will outline the rationale for the actual case study approach adopted within the context of this thesis.

4.5 What makes a case study a case study?

In case studies, data can be collected in various ways and from various sources (Gerring, 2007). Indeed, Yin (2009) outlines six sources of evidence which are commonly used in case studies: archival records, documentation, interviews, direct observations, participant-observations and artefacts. Such approaches to data collection do resonate with approaches ethnographers may also adopt, as intimated in previous narrative in section 4.3.3 of this chapter. However, within the context of case studies, each approach has strengths and limitations. No one approach is considered to have superseding advantage over any other, yet the use of multiple sources is considered advantageous (Yin, 2009). Therefore, the primary concern for researchers during the design of their case studies should be the identification of methods of data collection that facilitate the generation of suitable materials (Willig 2001). Whilst the use of a range of data collection methods allows exploration of the complexities associated to the context of a particular phenomenon (Willig, 2001), selection of these should be preceded by consideration of various methods to ensure that the most appropriate approaches are adopted within the context of any one study. Here, researchers should make judgements about the potential strengths and limitations of each approach. Thus, for such a purpose, Yin's list of six central types of evidence will be taken as the point of departure for the following discussion.

4.5.1 Sources of evidence

Firstly, interviews are regarded as the single most important source of evidence within the context of case studies (Yin, 2009). Interviews espouse themselves as a vital

component of case study research because important insights can be gained into human affairs or particular behavioural events (both central foci in case studies) from well-informed interviewees (Yin, 2009). The insights interviews afford are a considerable strength of this particular source of evidence, but should be considered with some cognisance of their potential limitations. For example, interviews can be subject to bias, both in terms of response bias and bias of data generated due to poorly articulated questions and there may be some inaccuracies due to poor recall of information or events and researcher presence in this interaction must be acknowledged within the context of their reflexive account (Yin, 2009). However, the strength of the information elicited in interviews surrounding participants' in-depth views and experiences has been recognised by other researchers who have conducted case study research (Hewitt-Taylor, 2002; McDonnell *et al.*, 2000; Payne *et al.*, 2007).

Secondly, archival records are often regarded as a key source of evidence within case study research. Examples of archival records include organisational records, maps and charts of the geographical characteristics of a particular location, computer files and public use documents, such as census data, or survey data (Yin, 2009). Evidence collected during archival review can be used in conjunction with other sources of information within the context of the case study, but researchers should note that the usefulness and applicability of such data is case dependent, as, in some studies, archival records will form a central component of the study, whereas in others, retrieval of such information will be of limited relevance (Hewitt-Taylor, 2002; Yin, 2009). However, it should be noted that retrieval of relevant or appropriate archive materials can be problematic as access may be deliberately withheld or obstructed due to privacy reasons (Yin, 2009). On the other hand, use of the third potential source of evidence, documentary review, may mean access to information is more readily available, as media documents like newspaper clippings or administrative documents, such as proposals or progress reports, can be included (Yin, 2009). Furthermore, Stake (1995) would argue that personal documents, such as letters, calendars or diaries, all legitimately offer themselves as additional relevant sources for documentary review. Regardless of the definitive type of documentation accessed, key to the use of such documentation within a case study is its use to "corroborate and augment evidence

from other sources" (Yin, 2009, p.103). This means that should such evidence gathered during documentary review be found to be contradictory rather than corroboratory, the problem can be further pursued by continued inquiries into the topic (Yin, 2009).

Fourthly, direct observations and fifthly, participant observations, are also considered additional potential sources of evidence within case studies. In terms of direct observations, opportunities for observations of this nature are a direct consequence of the case study occurring within the natural setting of the case (Yin, 2009). This means that potentially relevant behavioural and environmental conditions will present themselves for observation, with data collection activities ranging from formal to more casual in nature. In terms of formal activities, observational instruments can be constructed, with prompts for researchers to record occurrences of particular behaviours during particular periods of field work. Alternatively, less formal direct observations might be made as a consequence of other activities in the field, such as interviews, being conducted and the data collected (Yin, 2009). Participant-observation, on the other hand, is distinguished by the active role the researcher adopts within a case study situation, often participating in the very events one wishes to study (Yin, 2009). However, although observational evidence, either direct or participant-based, can provide detailed contextual information about a case, such activities are both time and labour intensive. The risks of selectivity in terms of observational data are high, particularly if a team of observers does not exist, as obtaining broad coverage is impossible by solo observers. Researchers should also be aware of their role within the context of the data that are produced – events being observed may proceed differently as a direct consequence of said observations – thus sensitive levels of researcher reflexivity are required (Yin, 2009).

Finally, physical artefacts may also be considered a potential source of evidence in case study. Often physical or cultural in nature – a work of art, an instrument, tool or particular technological device – they tend primarily to be used in anthropological research. The use of these sources within such work is often regarded as valuable, as such materials can provide useful insights into particular cultural features and may

contribute to ascertaining a level of knowledge which extends beyond that afforded by limited periods of field work (Yin, 2009).

Despite discussion of each of these potential sources of evidence singularly, a key defining feature of case studies is the inclusion of more than one source of evidence in any one case study. Thus a discussion of the merits of multiple perspectives within the context of case studies is considered in section 4.6 that follows.

4.6 Development of the current case study

Section 4.4.3 illustrated that the location of a case study along the design continuum should be cognisant of not only the aim, purpose and research questions of said study, but also of the philosophical positioning of the researcher. Yet, delineating case studies into specified designs such as those previously outlined in section 4.4.3 can be a complex task. For example, it could be argued that the current case study could be considered, in Yin's (2009) terms, as an embedded multiple-case design. That is, as the study was concerned with a particular health care phenomenon, that of the process of transition from one health care sector to another (paediatric to adult cancer services), the identification of particular NHS Board 'cases' in which this phenomenon was embedded, could have provided an avenue for exploration. The aim and purpose of this study was, however, not to conduct an evaluation of current transitional care service provision. The adherence to these criteria thus allowed the researcher to reject this approach, particularly as she was concerned that organisational structures surrounding transition would inappropriately ultimately bind this case, rather than the previously identified central feature of the project; people's experiences of the process of transition. Indeed, the overall focus of the current study was an exploration of young people, friends or family members, health care professionals and recorded case note information of the experience of the process of transition from paediatric to adult cancer care, thus consideration of multiple perspectives; a facet prioritised in case study research. This meant that a case study approach which would better permit an exploration of these experiences was required.

To this end, Stake's (1995) collective case study design was considered most appropriate for the purposes of the current study, particularly as such an approach permits the simultaneous study of a number of cases, to enquire into the population, particular phenomenon, or the general condition (Stake, 1994) of interest. Stake (1994) contends that such cases are studied in-depth and are chosen because one believes that understanding them will lead to better understanding and potentially better theorizing about a larger still collection of cases (Stake, 1994). This element married well with the purpose of current study, as not only was this study concerned with a collection of individual cases for which a range of data were collected, but also, it was further anticipated that such an approach would permit an in-depth and multiple perspective understanding of these cases.

This meant that in the current study, as the particular phenomenon of interest was the experience of the process of transition from paediatric to adult cancer services, a range of individuals were selected to represent exemplars of this phenomenon. This method provided the opportunity to study the phenomenon of transition and how this exists within and between such exemplars (Stake, 1994; Willig, 2001). Indeed, individuals experiencing the phenomenon of interest are considered appropriate cases to study and analyse (Willig, 2001). Thus, in the context of the current study, exemplars were young people, friends or family members, health care professionals and recorded case note information, as all were deemed to demonstrate knowledge and experience of the general phenomenon of interest.

The literature review in Chapter 3 revealed that the majority of previous transition research conducted to date had prioritised illnesses other than childhood cancer, with conditions such as diabetes, juvenile idiopathic arthritis and cystic fibrosis dominating the evidence base thus far. Comparatively, the empirical base of transition research with survivors of childhood cancer was deemed to be lacking, with relatively little known about the experiences of transition of young people, friends or family members and health care professionals. Thus, interviews were chosen as one of the key sources of evidence in this study, as these would allow the researcher "to find out what is in and on someone else's mind" (Patton, 2002, p.341). Moreover, interviews were

selected as they offer one of the most powerful ways in which we seek to understand "our fellow human beings" (Fontana and Frey, 1998, p.47).

In addition, the literature review had suggested that there might be some inconsistency in terms of recorded clinical information surrounding transition, and what was recorded was rarely considered simultaneously to people's experiences of the phenomenon. Therefore, the researcher wanted to explore what information was recorded about people's experiences of transition in order to see where similarities and differences in people's narratives could be identified. For this reason, documentary reviews, specifically oncology case note reviews, were conducted, as the inclusion of documents such as these can be valuable "because of what can be learned directly from them" (Patton, 2002, p.294).

In summary, a collective, exploratory case study approach, which considered multiple perspectives, was considered the most applicable for this doctoral research for reasons that are threefold. Firstly, the role of the researcher in the research process and generation of meaning from the findings from the study is honoured, thus ensuring resonance with the researcher's epistemological position within the constructivist-interpretive paradigm in the context of this study. Secondly, the experiences of the various participants binding the case study would be explored, and thirdly, the case study approach permits the consideration of multiple perspectives of these experiences, thereby increasing understanding of the phenomenon.

4.7 Chapter Summary

In this chapter, the researcher has sought to outline the philosophical underpinnings adopted within the context of this research study. The chapter introduced the philosophical position adopted for this thesis, that of a constructivist-interpretive stance, and the influence of this in the development of the project. The adopted philosophical positioning was then examined within the context of reviewing particular strategies of inquiry considered for this study, which consequently informed the research approach adopted. Thus, discussion in this chapter has illustrated and

justified the decision to adopt a case study approach for this study. The conduct of the case study is explicated in Chapter 5 that follows. Chapter 5 details the pertinent issues of the study methods, including specific details of data collection, ethical issues, the researcher's reflexive account and the adopted approach to analysis.

Chapter 5 Methods, Data Collection, Ethical Issues

5.1 Introduction

The discussion in the previous chapter justified the reasons for the adoption of a qualitative case study, in which multiple perspectives were embedded, to explore the experiences of young people, their friends or family members, key health care professionals (HCP) and recorded case note information of the process of transition. Building on this discussion, the current chapter further details the case study by manner of considering the methods adopted within the context of the study's aim and research question. This chapter will also discuss the study sample and ethical aspects of the research and will detail the analytic framework adopted in this study.

5.2 Study aim

This study sought to consider the experiences of young people who are survivors of childhood cancer, their self-nominated friends or family members and self-nominated key health care professionals of the process of transition from paediatric to adult cancer services, by manner of a qualitative case study in which interviews and case note reviews were conducted. It was anticipated that this exploratory study would advance and ground an understanding of this phenomenon from an experiential perspective. In order to address this aim, the following research question was posed:

- What are the experiences of young people who are survivors of childhood cancer, their self-nominated friends or family members and self-nominated health care professionals of the process of transition from paediatric to adult cancer services?

5.3 Study design

This was a qualitative study, informed by a case study approach which considered multiple perspectives, and which sought to recruit up to 16 young people who were survivors of childhood cancer to participate in individual semi-structured interviews.

Initially, it was anticipated that this study would be longitudinal in nature, with repeated interviews conducted with individuals at two distinct stages of the transition process: prior to first attendance at the adult sector, and again following this first appointment. Yet, as will be revealed in section 5.10 on pages 166-169 which details the pilot work conducted, this approach was not possible due to difficulties with recruitment. Therefore, the design adopted in the current study was the recruitment of two groups of young people who were interviewed once: one group who had just had their last long-term follow-up appointment at the paediatric hospital (up to n=8) and one group who had just had their first long-term follow-up appointment in the adult hospital (up to n=8). Each young person was asked to nominate a friend or family member and a HCP to also participate in individual interviews. Further, the case notes of each young person were to be reviewed.

5.3.1 Study Sites

Young people were recruited from two NHS Board areas in Central Scotland; people from multiple geographic regions across Scotland access the services provided by these Boards. Participants were recruited from a total of three hospitals from across these areas; one paediatric hospital and one adult cancer centre in one area and one paediatric hospital in the other. During the project initiation, it was suggested by a Paediatric Oncologist that per annum, one of the paediatric hospitals transfers the care of approximately 40 young people who are at least five years post-diagnosis to the adult cancer centre (Murphy, 2008). It further emerged that a minimal number of young people move within the first five years following diagnosis and very rarely whilst receiving active treatment.

5.3.2 Selected sources of evidence

It was discussed previously in Chapter 4 that case study research is notable for its use of a range of data collection methods. It was also considered how the potential for the use of a range of data collection methods permits detailed exploration of the complexities associated to the context of a particular phenomenon (Willig, 2001). In this study, interviews and documentary review were identified as the core sources of

evidence, with further rationale for this revealed in forthcoming sections, namely 5.3.2.1 and 5.3.2.2.

5.3.2.1 Interviews

The experience of the process of transition from paediatric to adult cancer services for long-term follow-up care was central to this study. To allow such a human affair (Yin, 2009) to be explored, a source of evidence was required which would allow participants' experiences, opinions and beliefs of this particular affair to be heard. Thus, interviews most immediately presented as an essential and central source of data within the context of this qualitative study. Interviews expedite the in-depth exploration of central issues within the context of the case, and provide an avenue for researchers to ask follow-up questions (Simons, 2009). Thus, interviews were selected as the primary source of data collection as qualitative interviews are considered to be the most appropriate for researchers who wish to access a participant's own understandings and experiences of the world (Taylor, 2005). As Taylor (2005) suggests, interviews are a useful method to explore sensitive issues or topics, which may not be as accessible through methods such as structured questionnaires. She further states that the aim of the qualitative interview is "to explore the 'insider perspective'. To capture, in the participants' own words, their thoughts, perceptions, feelings and experiences" (Taylor, 2005, p.39). Furthermore, qualitative interviews allow the researcher to explore the variations in human experience and develop an understanding of the world from the participants' point of view (Kvale, 2006).

However, to best access these experiences, some consideration was required in terms of selecting the most appropriate interviewing approach from the myriad of styles that exists across qualitative research literature. Interviews may be structured, semi-structured, in-depth, narrative, biographic, or open, to list but a few of the approaches and terms that pepper the discourse across the literature. The structure of the interview dictates the form the interview takes, with two ends of the continuum: completely structured, where the researcher cannot deviate at all from the questions provided on their schedule, to completely unstructured, where the interviewer does

not have a schedule of predetermined questions, and instead the interaction takes on the form of a conversation (Haralambos and Holborn, 2000). Somewhere within the boundaries of these two extremes is where the majority of interviews actually fall (Haralambos and Holborn, 2000) and that may be commonly referred to as semi-structured interviewing.

Within the context of case study interviews, similar distinctive terminological boundaries exist. In case studies, in-depth interviews can be used as these interactions afford the opportunity to ask participants about the facts of a particular matter, and, in addition, their opinions about events (akin to the unstructured interviewing approach above). Alternatively, a focused interview may be conducted, in which a person is interviewed for approximately one hour, in a conversational manner, but with questioning informed and driven by the protocol (Yin, 2009) (this method suggests that a semi-structured approach is adopted and the interview technique lies at the mid-boundary location of the majority of interviews). Further still, interviews may be conducted which have a structured line of questioning, meaning they may be referred to more appropriately as a formal survey (the structured end of the continuum aforementioned). This final approach can produce quantitative data within the context of the case study, but is only deemed an appropriate strategy to adopt if the purpose of that case study so permits.

Thus, within the context of the current study, it was necessary to adopt an interviewing approach that allowed all participants to be asked particular questions about transition, but that also provided an avenue in which the individuality of people's experiences could be explored and understood. Hence, semi-structured interviews were selected as the most appropriate approach for this study. Semi-structured interviews allow participants to talk about a particular element of their experience or life that the researcher is interested in (Willig, 2001). The researcher asks the participant particular trigger questions, thereby encouraging the participant to tell their story (Willig, 2001). The researcher's questions steer the interview, to allow data to be obtained that will answer the research questions (Willig, 2001). As an

addition, in the current study, the researcher was interested to hear about a particular experience from a triad of perspectives within the context of each unit of analysis.

Thus, like Yin (2009), in this instance, the researcher was favourable of the approach of asking respondents, or key informants, for suggestions of other people to interview for further exploration of the experience. In so doing, additional sources of evidence which may have corroborated or contradicted the evidence presented thus far (Yin, 2009) would be revealed. Therefore, to do this, the researcher asked the central component of each case, the young person, to self-nominate the friend or family member and health care professional for participation.

To reflect the changing nature of young people's relationships, the term 'friend or family member' was adopted to recognise the increasing importance and significance that social networks of young people play in their overall well-being (Royal College of Nursing, 2008). This strategy provided the young person participant with the control and power to nominate who they felt had been an important part of their health care and transition experience, rather than this being pre-determined. By seeking to explore the transition experience from the perspective of the friend or family member, it was anticipated that some similarities in the experience may be revealed, thereby corroborating the young person's experience. It was, however, also expected that some unique individualities would, too, be revealed from the perspective of this individual, thereby providing a possible line of contradictory evidence for consideration.

Finally, in terms of the interviews, to provide yet a further avenue to help develop the understanding of each individual case, and, subsequently, the wider context of the phenomenon, each young person was asked to nominate a health care professional they felt had been important during their care at the paediatric hospital or to whom they had spoken about moving to adult care. The purpose of the interviews with these individuals was to explore and understand from the health care professionals' perspective what the process of transition was like for the young person.

5.3.2.2 Case Note Review

The interviews provided one level of evidence to explore and understand the experience of the process of transition from paediatric to adult cancer care services. However, as earlier discussion highlighted, considering multiple perspectives by means of multiple methods of data collection and sources of evidence are a key distinguishing feature of case studies and were features embedded in the current study. Thus, to provide an additional level of evidence, and to further explore the potential corroboratory and/or contradictory nature of this method, an additional source of data was selected for inclusion in the current case study, that of a documentary review. A particular document type presented itself as the most feasible and useful to review for evidence of each young person's transition experience: their case notes. The reasons for the appropriateness of this review are fourfold: each patient would have a source of additional data for exploration readily available (should consent for access be granted by the patient); the data contained within these documents exist prior to the research study (thus generation of these has not been influenced by the researcher); reviewing these would "corroborate and augment evidence from other sources" as Yin (2009, p.103) suggests; and finally, they provide a suitable avenue to further pursue the topic (experiences of the process of transition), as advocated by Yin (2009).

5.3.3 Study Population

In this study, each case comprised a number of distinct components. Firstly, two distinct groups of young people were to be recruited: one group who had just had their last long-term follow-up appointment at the paediatric hospital and one group who had just had their first long-term follow-up appointment at the adult hospital. Focusing on these two distinct stages of transition provided important context to help understand the process of transition, and, in so doing, helped explore and understand issues associated to leaving one care sector for another. In addition, each case also included self-nominated friends or family members and self-nominated HCPs of the young people. Further, for each young person, a review of their case notes provided the final component of each case. Thus, for each case, the intended units of analysis are displayed in Table 4:

Table 4: Sources of evidence collected per individual case

Cases 1-16	Young Person Interview	Self-Nominated Friend or family member Interview	Self-Nominated Health Professional Interview	Paediatric Case Note Review	Adult Case Note Review

In terms of young people, the study sought to recruit those who were survivors of childhood cancer and who were at least five years from the point of diagnosis. Recruiting people who are at least five years post-diagnosis fits with definitions of entering long-term survivorship (MacLean *et al*., 1996) and is the recommended point at which the development of late effects are monitored, through regular, systematic and life-long assessments (Freyer and Kibrick-Lazear, 2006).

5.3.3.1 Inclusion and exclusion criteria

A number of specific inclusion criteria were outlined for the young people participants in this study. Young people were eligible for participation in the study if they had been diagnosed and treated for cancer (either oncological or haematological) between the ages of 0 and 16 but were aged 15 years (the youngest age at which transfer to adult care would actually occur (Murphy, 2008)) or over at the time of recruitment. Each individual was required to be at least five years from the time of their initial cancer diagnosis, able to communicate in English, willing to participate in an individual interview with the researcher and provide written informed consent/assent. Participants with palliative care needs were excluded from this study as the focus was on the experiences of those participants considered to be long-term survivors of childhood cancer.

Furthermore, young people were required to nominate a friend or family member to prove eligible for participation, to ensure consistency in the dyadic exploration of the experience. In addition, by placing the young person at the centre of each case, this meant they were responsible for the self-nomination of the friend or family member and the health professional participants who, too, would be interviewed.

In terms of the friend or family member and health professional participants, particular inclusion criteria were also established to ensure their eligibility. Such criteria were: nominated by the young person to participate in an interview; willing to be interviewed individually from the person who nominated them; able to communicate in English; and able to provide written informed consent.

5.3.4 Sampling strategy

A purposive recruitment strategy was employed for this study. In so doing, it was anticipated that cases deemed to be information-rich in the context of this study and its research questions would be selected, to provide an understanding and knowledge of this phenomenon. A number of other sampling strategies were, however, considered and rejected prior to adopting this approach.

Probability sampling, that which is traditionally applied to and the most rigorous approach for statistical research, is commonly considered inappropriate for application in qualitative research (Ritchie *et al.*, 2003a). Instead, qualitative research selects non-probability samples, which chooses units deliberately "to reflect particular features of or groups within the sampled population" (Ritchie *et al.*, 2003a, p.78). A variety of sampling approaches have been developed to help facilitate these selections in qualitative research. Approaches can vary from being purposive or criterion-based, to being theoretical to opportunistic and convenience sampling (Ritchie *et al.*, 2003a). Indeed, purposive or criterion-based sampling are the most common approaches employed, with a variety of more specific sampling strategies under these broad umbrella terms available for application, dependent upon the aim and purpose of the study. Some examples of these purposive sampling strategies include: homogeneous samples, in which individuals are chosen as they have the same characteristics; maximum variation sampling, which deliberately seeks to include individuals with contrasting characteristics; deviant sampling, which chooses cases due to their unusual or special characteristics; or intensity sampling, in which cases are selected if they strongly represent the phenomena of interest (Patton, 2002; Ritchie *et al.*, 2003a).

Purposive approaches to sampling such as these are generally considered the most fitting to produce information-rich cases.

Thus, a purposive sampling strategy was the most appropriate to apply in this study, as it was necessary to recruit individuals who met the established purposive criteria and who could provide exemplar perspectives of the phenomenon (the process of transition from paediatric to adult cancer services). Moreover, the predominant purposive criteria applied to the recruitment of young people in the current study include their stage of their transition (post-last paediatric or post-first adult appointment), their diagnostic grouping (haematological or oncological) and their age at diagnosis (0-10 years or 10-16 years).

5.3.5 Sample Size

In a case study, the term 'sample' is said to refer to "whatever cases are subjected to formal analysis; they are the immediate subject of a study or case study" (Gerring, 2007, p.21). But just how many cases one actually requires often arises within case study literature in the context of sample size discussions. Some believe the sample size must be small, consisting of either a single case or a handful of cases (Gerring, 2007), others believe the number of cases for selection should be based on the number of literal and theoretical case replications required or desired for a study (Yin, 2009), and yet others believe that case study research does not constitute sampling research (Stake, 1995). However, a helpful distinguishing feature drawn upon within the context of the current study is a consideration of the thoroughness with which each case that falls within the sample is to be studied (Gerring, 2007). The more case studies a researcher has, the less likely each one will be studied intensively, therefore, practicality-wise, it is not unusual for a case study to limit itself to a dozen cases, or even fewer (single cases are not unusual) (Gerring, 2007).

As the discourse in the latter part of section 5.3.4 indicated, a purposive sampling strategy was adopted in this case study. Therefore, in the context of a triad of issues – the purposive sampling strategy, ongoing debates about the selection of an

appropriate sample size, and the study design – the researcher was keen to select a number of cases that would both be practical within the time confines available to her as a solo researcher and from which an in-depth understanding of the exemplar perspectives of the phenomenon of transition could be generated. Therefore, from the study design perspective, the inclusion of one group who would have just left paediatric care and another group who would have just attended adult care, it was considered appropriate to recruit up to eight young people from each of these sectors, and therefore up to a total of 16 young people overall in the study. Including up to eight young people from each sector was regarded as appropriate within the context of the purposive criteria and research questions previously outlined, thereby allowing for the selection of information-rich exemplar cases.

In addition, as each young person was asked to nominate a friend or family member and a health care professional for interview, as well as their case notes being reviewed, it was further expected that n=16 friends or family members, n=16 health care professionals and n=32 sets of case notes (if every young person had a paediatric and an adult file available) would also be included. It was, therefore, expected that a total of 16 cases in which the consideration of multiple perspectives would be assured, would be recruited for this study.

5.3.6 Recruitment

5.3.6.1 Young people participants

Following discussion with the clinical collaborators and after the pilot study had been conducted (to be discussed in due course in section 5.10), the researcher attended fortnightly haematology long-term late effect follow-up clinics at one paediatric hospital and fortnightly haematology and oncology long-term follow-up clinics at the adult hospital. In addition, the oncology long-term late effects clinic at this same paediatric hospital was frequented, as was the late effects clinic at the second paediatric hospital. To identify potentially eligible participants, the researcher liaised with the Young Adult Clinical Nurse Specialist (CNS) or the Paediatric Oncologist/Haematologist 2-4 weeks in advance, as far as possible, of each of these

clinics so they may have indicated to the researcher the potential number of last attendees at the paediatric clinic and the potential number of new attendees at the adult clinic. This strategy allowed the researcher to have a presence in the waiting area of these clinics. The same strategy was repeatedly attempted with the oncology long-term follow-up service at the first paediatric hospital, but the systems available to alert the Young Adult CNS responsible for this clinic of these potential last attendees were not as structured. Thus, attendance here was more sporadic and opportunistic.

A recruitment strategy such as this was beneficial as this allowed the researcher to directly approach young people immediately after their consultation, during which the study was verbally introduced to them by the Consultant and/or CNS. If the young person verbally consented to hear more about the study and their potential participation, he/she was taken to the researcher in the waiting area, where they were briefly introduced by the Consultant/CNS. At this point, the researcher would lead the young person (and often their parent) to a quiet space in the waiting area to further discuss the study and their participation. The researcher would introduce herself, her role, and the title of the study with a brief overview of its aim and purpose, practical aspects of involvement and issues around confidentiality, and withdrawal from the study. Often during these conversations the parent would sit beside the young person, but the researcher would very consciously direct the conversation to the young person, engaging and maintaining predominant eye contact with this person during the discussion. The parents were not ignored during these interactions; eye contact and engaging conversational gestures were made to them, too, during these introductions, but for the researcher, addressing the young person directly was a key behavioural decision in her recruitment strategy. Doing so, it was anticipated, would convey that the researcher respected their status as young people. If the young person indicated they were willing to consider their participation in the study, they were provided with an information sheet (see Appendix 2) for themselves and an information sheet which they were asked to give to their friend or family member (Appendix 3) whom they wished to nominate to participate in the study. It was explained to the young people that the purpose of the introduction at that time was not to conduct the interview nor for them to provide a definitive answer in regards to

their participation. Rather, it was merely an opportunity for the two parties to meet and allow them to 'put a face to a name' when the researcher followed them up. It was stressed that if they agreed for the researcher to do so, she would call them no less than 24 hours later to discuss participation, thereby providing an opportunity for them to read the study information and discuss this with any others they felt appropriate, prior to deciding whether or not to participate. For those who verbally consented to be followed up at this point, the researcher completed a 'consent to participate form' (see Appendix 4) for the young person, on which their contact details, diagnosis, age of diagnosis and the most appropriate time of the day to contact them were recorded. Each young person was asked to sign their form to indicate they consented for the researcher to have their details on record for recruitment purposes. Completed forms were stored securely at the University of Dundee.

Follow-up phone calls were made no less than 24 hours after these initial introductions. Those who indicated they wished to participate were also asked for the name and their relationship to their nominated friend or family member. At this time, interviews were scheduled as appropriate. For those who declined, a reason for doing so was sought and recorded as appropriate.

5.3.6.2 Friend or family member participants

During the follow-up phone call with the young person, they were asked for the name and relationship of their self-nominated friend or family member. In all cases, these nominations were a parent, and, most predominately, the mother. Often, the researcher had met the parent at the clinic during the initial introduction discussion, so the researcher was able to visualise this person, and vice versa. Whilst this previous introduction to the parent may be considered to have led to potential recruitment bias of the friend or family member sample, the fact that parents were still nominated by young people who attended their clinic appointment on their own (n=1 at the paediatric hospital and n=2 at the adult hospital) limits the potential for this bias. Further, given that each young person's reason for their nomination derived from the central role their parent played in their care and their overall cancer experience, this

suggests parents would still have been nominated, regardless of any prior introduction to the parent in the clinical setting. Thus, during the conversation with the young person to arrange the interview, clarification on the name of the parent was sought to aid greetings upon arrival at the home to conduct the interviews.

5.3.6.3 Health professional participants

At the time of their interview, each young person was asked to nominate a health care professional they believed had been important during their transition experience and/or during their cancer care experience. The reasons for this nomination were explained to young people and all consented for the researcher to contact a health care professional for interview. If a young person was unable to provide a name at the time of the interview and instead requested time to think of the most appropriate person to nominate, they were informed that the researcher would ask for this name the following day during the courtesy post-interview follow-up call. Each young person successfully nominated an individual for inclusion.

To arrange interviews with the nominated health professionals, direct email contact was made (if possible) by the researcher to introduce herself and the study, and to indicate that the health professional had been nominated by a young person for interview. On the occasions where direct contact with the health professional was problematic, access was sought through their personal secretaries. Following a period of email correspondence, a short telephone call was usually made to the HCP or secretary, to provide the name and date of birth of the young person who had nominated them to participate in the study. Young people were aware that the researcher would contact their nominated HCP to arrange an interview, thus confidentiality was maintained by ensuring only the HCP or their secretary were made aware of the reason for the interview. The purpose of the health care professional's involvement in the study was outlined during this period of correspondence, with a health professional information sheet provided (see Appendix 5). If in agreement, an interview was arranged between the researcher and the health professional, for a date and time as soon as viably possible.

5.4 Ethical Considerations

A number of ethical issues were considered in the development, implementation and conducting of this study. Ethical considerations are particularly important within the context of health care research, particularly so because any research which has an impact upon the lives of humans can generate ethical problems (Iphofen, 2005). A number of key issues warrant researchers' attention in the development of work of this nature, and the current study was no different. This section of the chapter will describe some of the pertinent ethical issues that were to be addressed in the current study. The first half of this section will focus on practical aspects of ethical considerations, such as gaining access to clinical sites, gaining ethical approval and obtaining informed consent, whilst the latter part will focus on issues relevant within the context of research of this nature – conducting interviews of a sensitive nature, the emotional well-being of participants and the emotional well-being and physical safety of the researcher.

5.4.1 Ethical Approval

This study was conceived and initiated at the University of Stirling; as such, ethical approval was received from the Department of Nursing and Midwifery Departmental Ethics Committee at the University of Stirling in June 2009. As required, NHS Ethical Approval was also sought: the West of Scotland Research Ethics Committee 2 approved the study in August 2009 (see Appendix 6 for approval letter). In addition, local Research and Development approval was received, as was approval from the adult hospital Clinical Trials Executive Committee (CTEC) in July 2009. A change in host institution of the researcher (from the University of Stirling to the University of Dundee in April 2010), required substantial amendment approval, as did some modifications made to the study design in October 2010 (see Appendix 7). As a result of the pilot work outlined in forthcoming section 5.10, the addition of a second hospital site to aid recruitment was also approved, as a minor amendment, in November 2010.

5.4.2 Gaining access to clinical sites

Establishing relationships and rapport with the clinical teams who would provide access to patients for this study was crucial to facilitate entry into the clinical sites, recruitment of participants and acceptance of the researcher's presence in the clinic waiting areas. To do so, a number of strategies were adopted. Firstly, a clinical supervisory relationship was established with a Consultant Paediatric Oncologist from one of the paediatric hospitals, which helped to facilitate initial access to the clinical team. The clinical supervisor arranged for the researcher to present her study at a monthly education session at the paediatric hospital in June 2009. This session was attended by a range of health professionals from both the paediatric and the adult oncology settings, thereby raising awareness and generating interest in the study. Secondly, the researcher liaised frequently with the clinical team during the recruitment period, and sought advice from both the clinical supervisor and key members of the clinical team in the development of revised recruitment strategies. Finally, subsidiary opportunities were presented to both raise awareness of the study and further build on the networks developed thus far through the researcher's membership of a number of national committees in the field and to which key members of the clinical teams also belonged.

5.4.3 Obtaining informed consent

All participants were required to provide written informed consent (written assent if aged under 16 years, alongside written consent from parents) prior to participating in an interview. Consent forms were created specifically for each participant group (see Appendices 8-11 for examples of the young people, friend or family member and health professional consent/assent forms, respectively). Adequate information must be presented to research participants in the information sheets to allow informed decisions in regards to participation, and therefore obtain informed consent, prior to participating in an interview. The NHS National Patient Safety Agency (NHS NPSA) (National Patient Safety Agency, 2008) provides guidance to researchers to construct such information. They advocate for a number of issues to be covered in the information sheet, and subsequently, the consent form, which potential participants

must read and understand before making a final decision in regards to participation. The NHS NPSA suggest that the type of information consent forms must cover includes confidentiality, data protection, communication with the patient's GP, voluntary nature of participating in the trial or study, and the right to withdraw. As such, these principles informed the construction of the consent forms developed for this study, with additional study-specific clauses, such as seeking consent to audio-record the interview (all participants) and obtain access to case notes and contact a health care professional (for the young people) included, as appropriate.

On the day of the interview, the researcher ensured that participants had read the study information sheet distributed at the time of recruitment and provided the opportunity for any further questions to be asked. Following this, the consent form was introduced. The researcher explained the necessity of such a document and talked through each statement on the form, obtaining a verbal understanding of each clause, prior to asking the participant to acknowledge each statement in the appropriate box, and to then print, date and sign the form. Participants were asked to complete two copies of the form – one for their own records and one for the researcher's records. On one occasion, verbal consent was provided by a young person – this individual was visually impaired. In this instance, each statement was read aloud by the researcher to the participant and his consent to each statement provided, usually by means of an 'aye, that's fine with me' response. Completed consent forms were stored securely in a locked filing cabinet in the researcher's office at the University of Dundee.

5.4.4 Talking about experiences of cancer

Prior to conducting the interviews for this study, the researcher was aware, due to previous research experience in the cancer care field, that talking about experiences of cancer could be a distressing experience for some participants. This awareness, coupled with evidence from the literature to suggest that providing the opportunity to participate in research can provide patients and their family members with a sense of purpose and meaning (Fine, 2003), dictated the ethos of the interviews. Thus, extreme

care was taken by the researcher to ensure interviews were conducted in a sensitive manner and participants' emotional responses could be managed appropriately. Participants were clearly informed that they had the right to halt an interview or participation in the study at any time with no impact on the care they receive. Whilst the study did not present any physical risks to participants, potentially emotive or sensitive discussions could have taken place. Thus, the researcher was alert to both any potential changes in the dynamic of the interview and participants' demeanour, continuously shaping her responses and the interview accordingly (Legard *et al.*, 2003).

5.4.5 Well-being of young people and friend or family members

Recognising some of the potential challenges raised in section 5.4.4, ensuring the well-being of participants was a fundamental concern for the researcher. As part of the debriefing procedure, young people were provided with the business cards and flyers for a range of local young people's cancer support organisations. It was stressed to young people that this information was left with every young person at the end of the interview, to avoid creating a feeling of being different to any of their study peers. The researcher emphasized to each young person that exploring this avenue of support was to be entirely their own choice; leaving such information was an ethical decision that had been made from the researcher's personal perspective. As a further line of follow-up, a courtesy telephone follow-up call was to be made to the young person the day after the interview to ensure their and their friends' or family members' well-being at that time; this strategy was implemented following discussions with the ethics committee at the time of review and approval. Both young people and friends or family members were made aware of this follow-up strategy, but assurance was provided that only with their consent would this phone call be made. However, no dyad refused this further contact. It was explained that the purpose of this phone call would be to enquire after both parties the day after the interview, recognising that during the interview interactions, experiences and memories may have been raised which had perhaps not been discussed for some time. It was further explained that if it was felt by either party during this follow-up discussion that any additional support was required at this time, the researcher and young person or friend or family member

would discuss from whom and where this support could be provided. If required, and only with verbal consent from the individual concerned, the researcher would contact such an individual on their behalf to raise awareness of the current situation.

5.4.6 Well-being and safety of the researcher

As the discussion in section 5.4.5 illustrated, recognising the emotional challenges of talking about experiences of cancer from the participants' perspective and ensuring their emotional well-being was an imperative concern in this study. Fundamentally, designing and conducting qualitative research of this nature must be cognisant of the needs of participants, but so too the needs of the researcher (Hughes, 2006; Dickson-Swift *et al.*, 2007).

Emotional and pastoral support was available to the researcher throughout the entire research study from the supervisory team. This support was particularly important during data collection to ensure the well-being of the researcher pre-, during and post-interview interactions. It was possible that, at times, participant responses and the content and nature of the interviews would be intensely emotive. It was important for the researcher to have opportunities, within the security of the supervisory team, to discuss these experiences from her own perspective and share, if required, her own emotional responses to such interactions.

In terms of researcher safety, the predominant issue was that of interview location – all interviews were conducted in participants' homes. As all the study sites serviced an expansive geographic area and a significant amount of travelling was required on the part of the researcher to conduct the interviews. Travel was conducted by train whenever possible, but at times, interview locations dictated travel by car or aeroplane. As the researcher had only met young people and friends or family members briefly (or sometimes never for this latter group) in the clinic area prior to the interview, a data collection safety 'buddy' system was implemented, such as that advocated by Hughes (2006).

Therefore, the established 'buddy' system was thus: a designated colleague or supervisor would be informed on the day of the interview that the buddy system would be required. This designated person was informed of the address, family name, time of the interview, number of interviews scheduled at that address (sometimes one, other times two) and expected time of departure from the house. In addition, on occasions where travelling by car was required, the researcher sent a text message to the designated buddy prior to leaving her own house and upon arriving at the participant's house, to indicate both that she had arrived safely and that she was now entering the home of the participant to conduct the interview. Immediately upon completing the interview and leaving the participant's home, this same buddy would be sent another text message or a telephone call made to notify that the interviews had been completed and she was on her return journey home. At this time, if the researcher required any support, in addition to her own debriefing procedure of capturing her thoughts, emotions, feelings and account of the interview experience in her reflexive journal, then the buddy served as an appropriate and immediate source on whom to 'offload'.

5.4.7 Confidentiality

Ensuring participants' confidentiality during research is crucial. However, on occasion, maintaining this confidentiality may have been problematic, particularly if any individuals required the input of specialist staff. However, individuals would have been informed of all subsequent courses of action post-interview by the researcher, if such an occasion arose. Anonymity was assured by allocating pseudonyms to participants, meaning that no identifiable information was associated to any of the data generated from the study. Confidential information from all participants was secured in a locked filing cabinet. Numerical identifiable codes used to assign participants with pseudonyms were, and still are, stored securely on password-protected computer files, accessible only to the researcher.

In terms of confidentiality between interview respondents, young people and their friends or family member participants were assured that conversations within that

dyad were confidential. In terms of the nominated health professional interviews, whilst these individuals were made aware of the name of the young person by whom they had been nominated, this was done with the young person's permission, but the narratives from the young people or friend or family members were not divulged or discussed within the context of these health professional interviews. The purpose of this strategy was, again, to ensure there was no breach between the previously assured confidentiality.

Finally, in terms of the case note reviews, no identifiable information was extracted from the notes. To ensure the extracted information corresponded to the appropriate young person, the case number assigned to that particular young person was recorded on the case note extraction sheet, rather than identifiable information such as their full name. Should the young person be referred to by name within any of the documentation extracted during the case note review, this name was simply replaced by '[name]' by the researcher in any documentation recorded. As with the transcripts and other data materials associated with data collection discussed earlier, extracted case note information was, and continues to be, stored securely on a password-protected computer file, accessible only by the researcher.

5.5 Data Collection

5.5.1 Rapport

With all interviews, on the day prior to the scheduled interview date, the researcher reconfirmed the availability of participants for her visit the following day. On the day of the actual interview itself, the researcher sought to engage each participant in some non-research/interview orientated discussion as much as possible prior to initiation of the interview, thereby helping to establish rapport. Such introductory moments within the research interaction are crucial and can help establish a relationship with the participant (Sharkey and Aggergaard Larsen, 2005). Indeed, ensuring that participants feel at ease and comfortable is a key skill of the qualitative interviewer – doing so fosters an environment in which the participant finds it much easier to talk to the researcher (Rapley, 2004).

In terms of young people and parental interviews, the nature of these rapport-building conversations upon initial arrival at the house included, as examples, the weather, travel arrangements to their house, introductions to pets if present, or complimentary comments on the location and/or appearance of their home. In addition, attempts were always made by the researcher prior to conducting the young people interviews to specifically engage them in conversation about their lifestyle, such as asking about their school or college work, where they worked, if appropriate, or what else they had planned for that day/evening after the interview. Similarly, prior to initiating the nominated health professional interviews, the researcher sought to establish rapport with these individuals, albeit such interactions were curtailed by time constraints to some extent.

5.5.2 Conducting the interviews

In semi-structured interviews, the researcher's research questions direct the interview. In so doing, this provides an opportunity for participants to talk about a particular aspect of their life or an experience in which the researcher is interested (Willig, 2001). The principals of this approach advocate that interview topic guides are created to help guide the interactions and to ensure the researcher does not deviate too far from the original research questions. The topic guides for this study contained a number of key areas to cover during the interviews, thereby allowing appropriate questions to be formulated throughout (Willig, 2001) and are contained in Appendices 12-14.

In terms of the young people and parental interviews, these all opened with a standard introduction, which again clarified what the researcher was interested in, and recounted when the researcher and the participant first met. Doing so was the trigger for the first broad opening question of the interview. Thus, as an example, the progression between reiterating the broad aim of study and the opening question was thus: "When we first met, it was your (or your son/daughter's) last appointment at [paediatric hospital]. Can you tell me what it was like to go to [paediatric hospital] for the last time?", or "When we first met, it was your (or your son/daughter's) first appointment at [adult hospital]. Can you tell me what it was like to go to [adult

hospital] for the first time?" During the interviews, the researcher consciously incorporated participants' statements into any probing questions that were asked, both to seek clarification that she had understood correctly what participants had told her, and to demonstrate to the participant that the researcher had been listening (Willig, 2001) and was interested in what they had to say.

The interviews with the nominated health professionals were conducted at their respective clinical sites in all cases except one. In this exceptional case, the nominated health professional was retired, thus the interview was conducted at a mutually agreed public location. During the recruitment process, health care professionals were made aware of the name of the young person who had nominated them for interview. Thus, it was stressed that the focus of the interview would be the experiences of that particular young person. To contextualise the young person in each of the health professional interviews, each interview opened with a broad question, which asked, "Why do you think [name] would have nominated you to take part today?" This approach both highlighted the focus of that individual within the interview and the experiential nature of the study. At times, the dialogue in these interviews wavered towards issues surrounding transitional care more generically, thus the researcher consciously attempted to re-focus attention on the specific young person at these times.

All interviews conducted in this study were audio recorded; no participant objected to the use of this technology. The audio recording device used – a small mp3 digital recorder - was reasonably discreet and was placed on the arm of the chair between the researcher and the participant or a nearby coffee table, or in the case of the professional interviews, on the professional's desk. Upon switching on the device and placing it as appropriate, it was not acknowledged again for the rest of the interview, save for the researcher occasionally glancing at it to ensure the recording light was still on.

All interviews with young people and parents were conducted at their homes, with ten of the eleven nominated health professionals interviews conducted in the clinical

setting. Young people and parental interviews were typically between 50 minutes and 1.5 hours in duration. Nominated health professional interviews were typically shorter in length, ranging between 20 and 30 minutes, primarily due to clinical commitments. All interviews were conducted face-to-face on a one-to-one basis, were digitally recorded and transcribed verbatim. Two interviews were transcribed by the researcher, with the remaining outsourced to an experienced audio typist. All transcripts, thus those self-transcribed and outsourced, were cross-checked for accuracy by listening back to the interview recording alongside reading of the transcribed document. Where possible, any initially inaudible sound bites were transcribed by the researcher prior to confirming the transcript as the approved final version for analytical use.

5.5.2.1 Well-being of participants during and following interviews

During the interviews, ongoing process consent, where consent is continually open to revision and questioning (Economic and Social Research Council, 2009), was obtained. Ensuring ongoing consent is particularly important if participants become distressed during an interview. In the interviews conducted in this study, on occasion, some participants did become emotional during the interaction.

A debriefing and follow-up procedure was implemented for young people following the interviews. The researcher contacted all young people the day after the interview to ensure their well-being following the experience of participating in the interview. Should the young person have indicated that they required some additional support during this follow-up contact or had the researcher identified this during the course of the interview interaction, the devised follow-up strategy was implemented. This procedure involved the researcher, with the young person's consent, contacting a member of staff from the hospital, primarily the Young Adult CNS, to request that contact was made with the young person to remind them of the services and additional support they could access.

5.5.3 Case note reviews

When obtaining informed consent, young people were asked for their consent for the researcher to access their case notes. It was explained to them that the purpose of this access was to review what further information was available about their transition experience from the clinical perspective. To conduct the reviews, the researcher liaised closely with the consultants' secretarial teams at the paediatric and adult hospitals as appropriate to request access to the files. As some files were in storage, access was often only available one to two weeks following the researcher's request. All case note reviews were conducted within the secretarial offices and all data were extracted and recorded manually in a matrix document (see template in Appendix 15). The matrix document was developed once a number of young people and friend or family member interviews had been conducted, with initial data familiarisation indicative of potential emergent descriptive themes. Thus, the matrix format served as an appropriate orientating tool during the documentary review processes and ensured these reviews were conducted in a way to ensure extracted data would add a valuable source of evidence within and between the cases in this study. Data recorded manually were later recorded in an electronic format to ease their integration with the interview transcripts, all of which were managed on NVivo for organisational purposes during the analytic stages of this study. Individual case note reviews typically took between 30 minutes and one hour, depending on the size of the file, and were conducted prior to the interview with the nominated health professional, as this provided further context for the researcher on the individual's experience.

5.6 Analytic Framework

It is possible, within the context of case study research, to either draw on an existing theoretical framework to inform and guide data collection, or for a theory to be generated from the data (Simons, 2009). Working within the confines of an existing theoretical framework can provide focus during the data collection activities, thereby aiding the analysis procedures, but there is a danger that data will be manipulated in such a way so as to fit the framework. Unexpected discoveries may therefore be missed (Simons, 2009). In contrast, if the theory is instead generated from the

gathered data, it is *"grounded in the 'lived' experience of participants in the case"* (Simons, 2009, p.33), which may lead the researcher to develop a unique understanding of the case. This latter approach requires some cognisance on the part of the researcher that such an approach can be time consuming and theory generation potentially complicated by complex and ambiguous qualitative data (Simons, 2009).

Nonetheless, within the context of the current study, it was necessary for the identification of an analysis framework which would allow some of those a priori issues embedded in the interview questions to be addressed, but which would, at the same time, be flexible enough to incorporate new issues which arose during data collection (McDonnell *et al.*, 2000). This further necessitated the use of a particular framework which would allow the research question established in this study to be addressed and to permit advancement of our understanding of the phenomenon of interest in the context of this study (the experience of the process of transition from paediatric to adult cancer services). To do so, an understanding was required first at the individual case level, prior to moving towards one at a collective level. A detailed exposition of the approaches adopted in this regard is provided throughout sections 5.7 and 5.8 of this chapter.

5.6.1 Approaches to qualitative analysis

Analysis of qualitative research places a particular dependence on, and recognises the interpretative skills of, the researcher (Snape and Spencer, 2003). Interpretation is the insight and understanding the researcher gains from both the formal analyses they conduct and the intuitive grasp they have of the data (Simons, 2009). As such, methods of analysis need to be practicable, communicable and reliable, from both the researcher's and the reader's perspectives. Indeed, analysis and interpretation should not be viewed as two distinct processes, but rather as one continuing evolving partnership:

> *Connecting themes identified through a specific analytic process may lead to a particular interpretation and so on.* (Simons, 2009, p.118)

The analysis process is, therefore, not linear. Instead, there is movement back and forth between stages of the analytic hierarchy and the various analytic tasks (Spencer *et al.*, 2003). Key within these processes of qualitative analysis is the need for the researcher to "capture, portray and explain the social worlds of the people under study" (Spencer *et al.*, 2003, p.213); this means researchers are required to stay as close as possible to the original data.

Approaches to qualitative analysis can, however, vary, depending on the tradition, approach, epistemological assumptions and positioning that the researcher has adopted (Spencer *et al.*, 2003). That said, a number of common defining features of qualitative analysis recur across the different approaches (Miles and Huberman, 1994; Ritchie *et al.*, 2003b; Simons, 2009). Miles and Huberman (1994, p.9) explicate a number of analytic moves considered to commonly appear in qualitative approaches to analysis:

- Affixing codes to a set of field notes drawn from observations or interviews
- Noting reflections or other remarks in the margins
- Sorting and sifting through these materials to identify similar phrases, relationships between variables, patterns, themes, distinct differences between subgroups, and common sequences
- Isolating these patterns and processes, commonalities and differences, and taking them out to the field in the next wave of data collection
- Gradually elaborating a small set of generalisations that cover the consistencies discerned in the database
- Confronting those generalisations with a formalised body of knowledge in the form of constructs of theories

Thus, qualitative analysis is both a rigorous and logical process through which data are given meaning (Gray, 2004; Barbour, 2008), with the processes likely to have some resonance to the stages outlined in the previous list, regardless of the particular tradition in which one is located. However, one cannot dismiss epistemological

positioning within the context of the analysis procedures. It was discussed previously in Chapter 4 how the constructivist-interpretive epistemological positioning has served as a basis for the current study. Thus, to maintain this framework throughout, it was necessary that an approach to analysis was adopted which would help facilitate the construction of the reader's knowledge, but also recognise the multiple constructed realities of the cases in this study.

To do this, approaches advocated by Miles and Huberman (1994) were used to underpin analysis in this study. Favouring inductive methods of study and keen to "account for events, rather than simply to document their sequence" (Miles and Huberman, 1994, p.4), their transcendental realist approach prompts them to seek out individual or social processes, or mechanisms or structures at the core of events. Although they regard themselves along the lineage of transcendental realism, they do, however, welcome debate surrounding the likelihood of researchers being rigidly aligned to one location on the epistemological continuum. It is, Miles and Huberman argue, "hard to find researchers encamped in one fixed place" (1994, p.4) along this continuum. Rather, they suggest, all researchers operate closer to the centre and not at opposing polar ends of such a continuum (Miles and Huberman, 1994). Thus, they welcome the interpretivist positioning and are supportive of the importance associated to meaning-making central to social life (Miles and Huberman, 1994).

In this regard, the analytic techniques proposed by these authors facilitate description, understanding and explanations of single cases *and* [emphasis added] multiple cases, thereby allowing more "sophisticated descriptions and more powerful explanations" to be developed (Miles and Huberman, 1994, p.172). The opportunity to present and represent such descriptions and explanations from multiple perspectives, by inductively generating analytic categories and concepts to describe and explain the data, is central to this study. The systematic and rigorous data analytic techniques proffered by Miles and Huberman (1994) therefore provided a means by which the cases in this study could be described, understood and explained. This method of analysis, Stake (1998) would argue, is fundamental to case studies, as a case study is as much about the process of learning about the case as it is the product of what we

learn from it. Indeed, in a collective case study, an understanding generated from the cases is considered a likely precursor to better theorising about a yet larger collection of cases (Stake, 1994). Therefore, this potential for improved theorising is congruent, not only with the premise of a collective case study, but also with the constructivist-interpretive positioning adopted in the current study.

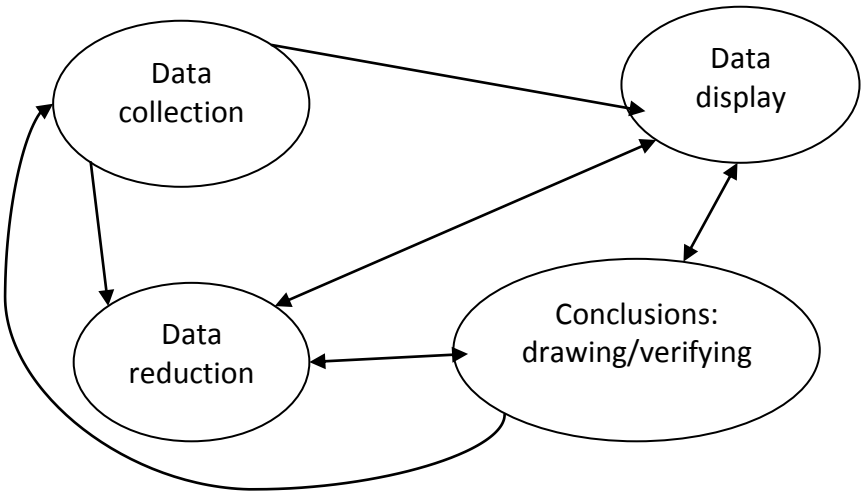
5.7 Analytic framework adopted in the current study

Within the context of the current study, it was necessary to identify an analysis framework which would allow some of those a priori issues embedded in the interview questions to be addressed, but which would, at the same time, be flexible enough to incorporate new issues which arose during data collection (McDonnell *et al.*, 2000). Thus, drawing on earlier discussion in section 5.6.1, the principles of a matrix-based approach to analysis advocated by Miles and Huberman (1994) were adopted in this study. Although the Framework Analysis approach developed by Ritchie and Spencer (1994) could have provided an alternative analytic framework for the current study, as it too utilises a matrix-based analytic method, the Miles and Huberman (1994) analysis framework was instead favoured. This was particularly so as this latter approach was considered appropriate to allow the research question posited in this study to be addressed as it honoured the generation of a multiple perspective understanding of transition prioritised in this collective, exploratory case study. Moreover, adopting the Miles and Huberman (1994) matrix-based analysis framework ensured that not only was an understanding of the experience of transition generated at an individual case level, but also at a collective level. This researcher considered such an approach appropriate to ensure that a humanistic understanding of the experience of transition was generated; as facet Stake (2004) considers key to the use of the case study.

5.7.1 Analysis of the data

Miles and Huberman (1994) use particular terminology to indicate the various components of data analysis: data reduction, data display, and conclusion-drawing and verification. These stages exist before, during and after data collection, in an interactive, cyclical process, as illustrated in Figure 3.

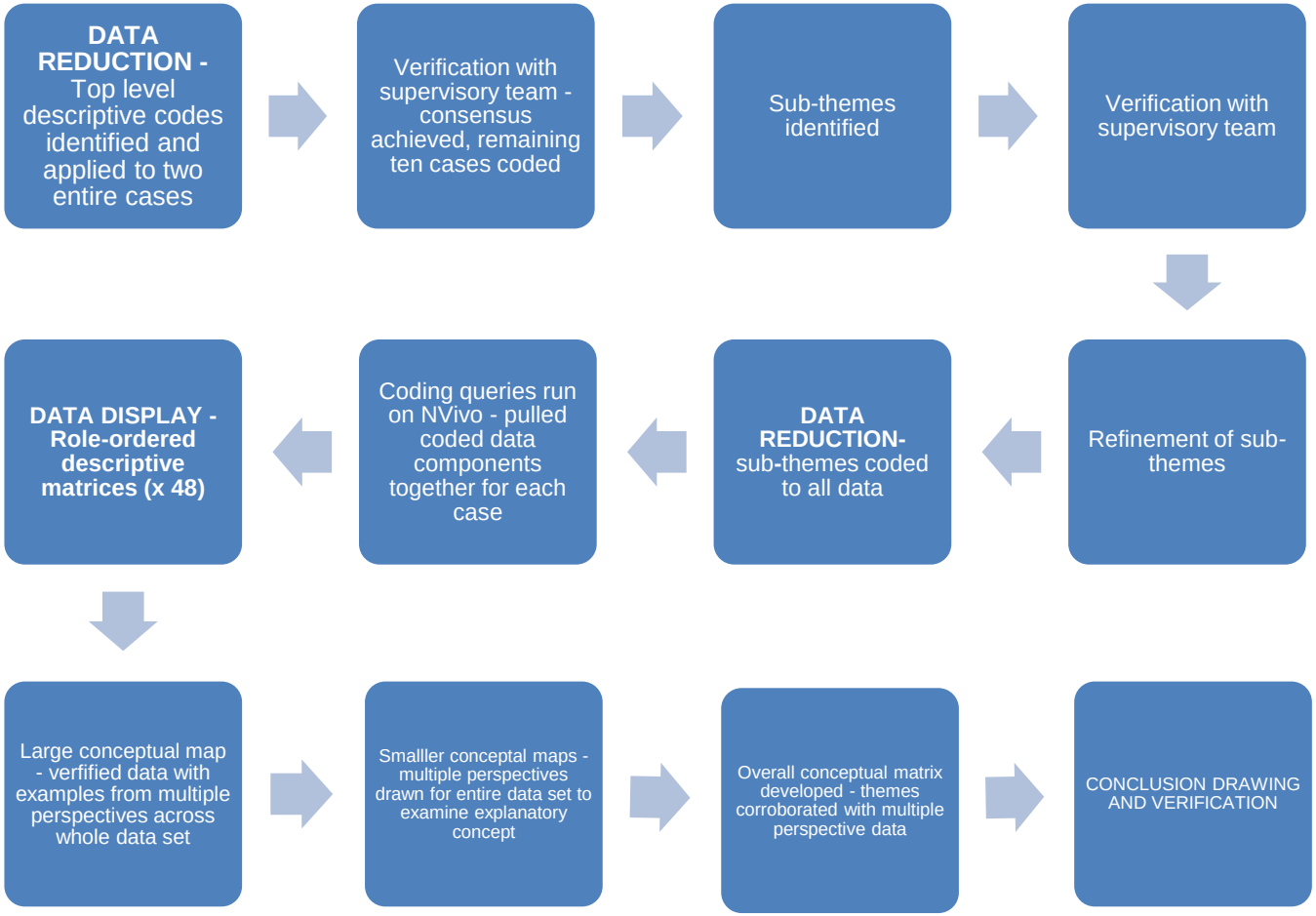
Figure 3: Components of data analysis: Interactive model



Reproduced from Miles and Huberman, 1994, p.12.

As Figure 3 demonstrates, the three streams of data reduction, data display and conclusion-drawing/verification are interwoven before, during and after data collection, and exist simultaneously to form the general domain of analysis (Miles and Huberman, 1994). Therefore, analysis of qualitative data is an ongoing, iterative process, but needs to be well-documented to foster credibility of the research, thus ensuring its validity (Golafshani, 2003). Validity is discussed in due course in section 5.9 within the current chapter. First, though, focus will remain on the three aforementioned streams; data reduction, data display and conclusion-drawing/verification, and the ways in which these were implemented as the key stages of analysis in this study. Figure 4 on page 151 visually summarises the stepwise approach to analysis adopted in this study. These stages ensured a full, in-depth and interpretative approach to analysis, explicated in detail in the narrative throughout section 5.8.

Figure 4: Summary of analytic processes (following data familiarisation)



5.8 Implementing the components of analysis: key stages

5.8.1 Data Familiarisation

The starting point for any qualitative analysis, upon checking the data are complete, is that of data familiarisation. During the familiarisation period, the researcher sought to gain an overview and become thoroughly acquainted with the data. She engaged in a number of activities to do so, including listening to the recordings of interviews alongside the verbatim transcripts, reading and re-reading the transcripts, documentary evidence and field notes. Such activities usefully facilitated the movement towards the subsequent stages of analysis, those of data reduction, data display and conceptual investigation and conclusion-drawing and verification.

5.8.2 Data Reduction

The process during analysis whereby data gathered from field notes or interview transcriptions are selected, focused, simplified, abstracted and transformed is referred to as data reduction by Miles and Huberman (1994). Essentially, data are reduced and are organised in such way to allow 'final' conclusions to be drawn and verified (Miles and Huberman, 1994). This stage is an important part of analysis as the choices a researcher makes in terms of sections of data to code, how to code them, and the evolving story to tell, are all classed as important analytic stages (Miles and Huberman, 1994). It is particularly crucial at this stage that data are not too far removed from the context in which they occur.

Indeed, data reduction, or coding, is the phase of analysis during which decisions are made in regards to the most appropriate ways of differentiating and combining collected data and their associated reflections. Codes are created and applied to descriptive or inferential information compiled during the study in various chunks and sizes; singular words, or collective phrases, sentences or whole paragraphs, for example. Miles and Huberman (1994) suggest that a list of codes is developed from the conceptual framework, the research questions, hypotheses and/or key areas that the researcher brings to a study. Codes allow the retrieval and organisation of chunks and sections of text, permitting the researcher to locate, extract and cluster segments

of text relating to a particular research question, theme or construct (Miles and Huberman, 1994). In the context of the current study, two interlinked data reduction stages were implemented.

5.8.2.1 Data reduction stage one: Top level descriptive coding

The first stage of analysis was to identify top level descriptive themes for coding. Following the recommendations of Miles and Huberman (1994), the researcher drew on the interview topic guides, the broad thematic areas of questions posed in the interviews and the themes identified in the case note data extraction matrices to do so. Thus, four key themes were identified, namely: transition, relationships, developmental aspects, and the experience of childhood cancer. In addition, a further general theme labelled 'other' was also included to ensure any emergent data that may not have been readily coded to any of the aforementioned themes were also reduced appropriately. These descriptive themes entailed little interpretation at this stage, but they were reflective of the main overarching themes of the interview schedule. Such themes were first attributed to the data on NVivo. NVivo is a software programme which the researcher elected to use to help facilitate the organisation and retrieval of data during this and subsequent phases, as this allowed her to store, code and cross-reference data from each case in one place. NVivo further permitted the organisation of data by case and by data source, thereby facilitating the ease at which data could be retrieved for the 'within' and 'between' analyses.

Therefore, at this first stage of data reduction, four themes emerged at the top of the analytical hierarchy. The entire data sets for two complete cases were then attributed to these four top level key themes. These coded cases were then verified with one member of the supervisory team, prior to any further progression, with discussion to ensure that consensus was achieved regarding the appropriateness of the coded themes. Following agreement, the remaining ten cases were also coded in this way. Throughout this descriptive coding process, the researcher manually noted potential descriptive sub-themes that emerged from the data. Such themes were recorded in a long list, under each of the associated key theme headings.

Again, prior to the application of any of these sub-themes to the data, verification with both members of the supervisory team was sought. On this occasion, the initial descriptive sub-theme list was discussed and the rationale for the emergent sub-themes examined. At this stage, discussion centred on condensing the long list of sub-themes, to permit movement from a descriptive to an interpretative level. Terms were combined, with such merging and refinement reflective of the researcher's interpretations of the data thus far and the verification discussions within the supervisory team.

5.8.2.2 Data reduction stage two: Sub-theme coding

Following such verification, the sub-themes were then applied to the full data set, to ensure further data reduction. Following the coding of the entire data set, a series of data queries were run on NVivo for each individual case for each of the main themes and sub-themes. Running a data query in this way permitted the generation of reduced data for each case collectively for the entire thematic structure developed. That is, the researcher was able to review the coded data for each case in its entirety, prior to moving towards the data display approaches adopted in this study.

5.8.3 Data display

Organising and displaying data is critical to permit the development of an understanding of what is happening within the data (Miles and Huberman, 1994), with a number of immediately accessible forms of data display, such as matrices, graphs, charts, and networks, advocated by these authors. Having compacted data in forms such as these permits the analyst to readily observe either occurrences in the data that allow the drawing of justified conclusions or occurrences which warrant movement to the next stage of analysis (Miles and Huberman, 1994). Data display processes are a central feature of analysis, as designing the display, and entering data in the appropriate cells are both critical analytic activities.

Within the current study, data were displayed via a series of matrices. Matrices, which are "essentially the 'crossing' of two lists, set up as rows and columns" (Miles and

Huberman, 1994, p.93), are one such data display technique that can reduce the use of extended, unreduced text; a form of data display that may be considered weak due to the potential for it to be poorly structured and very weighty (Miles and Huberman, 1994). In the context of the current study, though, such pitfalls of working with extended and unreduced text were circumvented by the use of matrices which displayed multiple perspective data at the individual (within-case) level and laterally at the multiple (cross-case) level. Moreover, such displays were considered appropriate in the current study as they were able to increase both the analytic power of the results and their readability (Miles and Huberman, 1994; Yin, 2009).

Miles and Huberman (1994) propose four main types of descriptive data display for addressing individual cases: partially-ordered display, time-orientated display, role-ordered matrices or conceptually-orientated displays, with a possibility that some displays may combine features across these types. In order to display the data in the most effective way in the context of the current study, the researcher had to ensure the specific matrix display selected was the most appropriate, to both facilitate further stages of analysis and to allow the research question to be addressed. As the study sought to capture the views and experiences of a certain set of *"role occupants"* (Miles and Huberman, 1994, p.123), that is, the young person, friend or family member, health care professional and case notes, the role-ordered matrix presented as the most viable for use, particularly so as the multiple perspectives captured in these matrices could help support emergent findings.

5.8.3.1 Within-case data displays: Role-ordered matrices

A matrix was developed for the four main descriptive themes introduced previously. The 'other' category was subsumed during the examination of the identified sub-themes, as discussed previously in section 5.8.2.1, as investigation of the data initially coded to this category indicated that they had better applicability within one of the four main themes identified. Data coded in this 'other' category referred to people's experiences of striving for some kind of normality within the context of their experience of childhood cancer, thus they were embedded within the 'experience of

childhood cancer' main descriptive theme. Adopting this strategy allowed individual matrices to be constructed for the four main themes of: the experience of transition, the experience of childhood cancer, experiences of relationships during illness in childhood, and developmental experiences in the context of transition. The columns of each matrix contained the associated interpretative sub-themes and each matrix displayed the multiple perspective data for each case. As an example, Table 5 illustrates one matrix from Case 06 to illustrate the process and contextualise the procedures that followed.

Table 5: Example of completed role-ordered matrix

Role-Ordered Matrix - Case 06: Experiences of transition			
ROLE	**Readiness**	**Expectations, perceptions and experiences**	**The significance of transition/the significance of moving on**
YP	Doesn't feel ready for going to A hosp and the expected changes going there involves, such as not having to depend on someone to tell people how she is feeling – worries she will miss things out, will be too embarrassed or won't know certain things or won't be totally honest with them. Had crossed her mind that she was too old to be attending P hosp but was still didn't expect to be leaving – was given option to go back once more 'but at the time, I was so upset and everything and I thought "I can't do this again"' – so knew would be even harder to leave in another 6 months, so decided just to leave now. Meeting the new Dr was helpful, but initially didn't know why a Dr from A hosp was talking to her 'it was so confusing at the time'. ***Planning & Preparation – lack of – impact on readiness for transition & to actually leave P hosp/longevity of childhood cancer experience –***	Has a picture of how expects A hosp to be – 'I can imagine it not being very pretty. I can imagine it being quite, you know, blank and plain and old and scary'. Also thinks approaches to blood tests will be very different compared to P hosp – no talk of magic cream – 'I can just imagine them being just like "right…arm…blood". Is worried and scared for going to A hosp as doesn't know what to expect but at same time says she should 'man up to it and just go myself' – may find that going isn't actually as bad as she is expecting it to be at this stage. Expects to be both anxious and excited in lead up to first appt there. ***Negative expectation of adult care – links to planning and preparation as some uncertainty what it will be like/fear associated to going there/developmental changes – more responsibility***	Very emotional when heard would be leaving, burst into tears soon as Dr told her, felt like has spent most of her life in P hosp, felt guilty in a way was leaving. Felt was leaving part of herself behind in P hosp. Finds the fact she is better upsetting – doesn't want to let it go. Would have liked to have thanked staff for so many things – doesn't want them to think she doesn't appreciate what they did for her now she is leaving. Feelings of guilt too –'it's just kind of a feeling of guilt because you're just leaving like such a big thing behind'. Move signifies that she is better 'and it's all over'. Move is also part of her growing up, time for her to mature. End of an era – end of big dramatic and emotional part of her life. Achievement to be able to leave –'I've beat something a lot of people die from'. ***Longevity of experience – loss of self,***

	knowledge of health care – impact on readiness		***relationships, P hosp/moving on from illness – impact on readiness? Better able to cope? But compare with other elements of her narrative***
PARENT	Doesn't know anything about A hosp, not been given any information about it – but wonders if this is because they think it's no longer anything to do with her. Nobody told her the move would be taking place – found this disappointing, so things could have been handled better, wasn't prepared for leaving. Found it such a shock to leave – would have preferred more time to get used to the idea – perhaps met the consultant this time, but then leave after next appt. Thinks her daughter isn't yet ready to leave P hosp and her leaving isn't important, it's all about her daughter. ***Planning & preparation – lack of/Loss/Impact on readiness to leave***	Doesn't know what staff will be like @ A hosp – all the nurses @ P hosp were very caring and cared about them, but she doesn't know how much time the nurses @ A hosp will have to spend with her and her daughter. Unsure what will happen with daughters pancreatitis LTFU – unsure whether this will be in adult care now aswell or if will have to go back to P hosp. Can't think what A hosp may be like, but thought new Dr was nice, so that is a good sign. Told a little by Dr about differences in set-up of A clinic re blood tests – perhaps won't get any done @ A clinic – having those done @ P hosp was 'a wee security thing'. ***Relationships – significance for parent with HCPs/longevity of experience/loss of security and safety/uncertainty about clinic set-up and LTFU – impact on readiness to actually leave?***	Leaving P hosp - ending to that chapter in their lives – is a positive thing that Drs want her daughter to move on, but was still a shock to find out the way they did. Is slightly scared about the prospect of A care though as it means her daughter is becoming an adult and won't need her mother anymore – things will be out of her control. Hopes this is the stage where her daughter 'just goes on and blossoms and turns into this lovely woman and you know has a long and healthy life'. Hopes it means they 'move on from it' – but it will always be there – which she hadn't appreciated. ***Longevity of experience – but chance to move on from illness in many ways /planning & preparation – lack of – impact on readiness as feels scared***
NOM PROF	Didn't have any direct involvement in YP's transition to adult care, decision to	On the YP leaving P hosp & going to A hosp - 'I imagine that X, you know	Does find it sad in many ways that the YP and parents have to move on from

	transfer usually based on age of the YP. Said she saw the YP & her mum after they found out they were leaving, said her mum's reaction was like 'you know, the usual' – didn't want to go, concerns about how she would manage as daughter was now to do things by herself. Thinks both the YP & her mother would have been ready to leave P hosp – although the mother might not have thought they were. Although people initially concerned about not being able to cope without P hosp 'they all manage at the end of the day'. ***Planning & Preparation – lack of involvement from her part/Note reference to 'usual' response – says both were ready to leave – but contrasts with YP and parent narratives – so where is the individualised approach to transition***	would just go and get on with it, she was that kinda girl'. Thinks that transition will be a bit easier now for YP with leukaemia - now there is a dedicated adolescent consultant appointed – 'with the leukaemics it's maybe a bit easier now because X is there and sees them'. Thinks none of the parents ever want to leave P hosp but 'the kids, like I say sometimes you know it's like, it's like water off a ducks back'. Thinks that when YP do move to the adult sector that they are 'probably looked after adequately but just not looked after…you know, in the same way.' ***Readiness – expects YP just to get on with being at adult hosp – but contrasts with YP's narrative/ planning & preparation – better due to assigned consultant***	P hosp, but *'they have to'* and states 'as the one lot move out, there's another lot kind of coming in'. YP moving to adult care is a natural progression – states that everybody needs to get on with their life, so the YP and families 'need to get away out of here and forget about this and get on' – so moving away from the illness more. Moving on might be different for the YP and their parents 'I think the children are often perfectly well able to move on, in many ways a lot better than their parents'. ***Longevity of experience – but need to move on from illness – but are people ready to? What support do they have to do so?***
CASE NOTES (P & A)	Letter in A notes following last appt @ P hosp – 'We plan now to transition her to the adult service at [adult hospital]…' This letter also included reference to the YP's last pancreatitis episode – notes delayed presentation due to concerns about attending adult surgical	No relevant data evident	No relevant data evident

	unit. A letter about this episode was contained in the P notes from her GP – this also noted her concerns about attending adult care & asked if there was any help that could be offered to the YP to make the transition easier. Response letter indicated YP would be introduced to adolescent consultant and stated 'we will not rush to send her to [adult hospital] and wait until she is comfortable'. ***Planning & Preparation – lack of – impact on her readiness to go and concerns about attending adult care – is the last quote above representative of her experience? Contrasts to her narrative of what happened – clear impact on her readiness to leave***		

Key:

YP = young person; P hosp = paediatric hospital; A hosp = adult hospital; LTFU = long-term follow-up; Appt = appointment

To complete the matrices, previously coded data from the transcripts and the case note reviews extracted from the NVivo data queries for each individual case were summarised in the relevant matrix, noting cross-references to other matrices and/or themes as appropriate. In total, 48 matrices were developed, with examples of the other three completed matrices for Case 06 included in Appendix 16 for demonstrative purposes. These role-ordered matrices allowed the identification of similarities and differences of experiences within and between cases, whilst simultaneously providing the opportunity to gain an initial overall understanding of the experience of transition for all the cases in the study. During the construction of each matrix, the researcher began the initial processes of drawing meaning from the data in the displays by noting patterns and themes emerging from the data as she made the initial move from the descriptive to the explanatory (Miles and Huberman, 1994). To do this, the researcher noted such meanings in bold italics, as exemplified in Table 5 previously. Organising and structuring the data in this way was crucial to facilitate the drawing and verification of conclusions.

A number of subsequent stages defined the ways in which conclusions were drawn and verified in this study. These stages are discussed in detail in the forthcoming chapter, Chapter 6 Introduction to the results chapters.

5.9 Validity

Validity, as defined by Willig is “the extent to which our research describes, measures or explains what it aims to describe, measure or explain” (2001, p.16). Similarly, for Simons (2009), validity within qualitative inquiry is particularly important as it helps researchers justify why those who read their work can trust the findings. Validity is concerned with the soundness of the qualitative work, its coherence and its appropriateness to the case (Simons, 2009), and can be conceived and justified in different ways. Within the context of case study research, Simons (2009) states that the choices of validation strategies are dictated by the following: the kind of case study being conducted, the purpose of the study, the methods used, and the audiences the research seeks to influence. Thus, various strategies are available to researchers to inform readers of their work that issues surrounding validity have been

considered. In the context of case study research, Simons (2009) states that two validation strategies are predominately advocated: triangulation and respondent validation. Although she suggests that neither strategy can ensure validity, rather only contribute to it, the decision about which strategy to adopt must be based on its appropriateness in the context of the kind of case study being conducted (Simons, 2009). Therefore, in the context of the current study, triangulation was adopted throughout, as this reflected the inherent approach to this study; the acknowledgment of multiple perspectives. Indeed, the extent to which these multiple perspectives have informed and been embedded within the current study has been demonstrated not only throughout this chapter, but also within Chapter 4, previously. Moreover, multiple perspectives are central not only the results Chapters 6 and 7 that follow this methods chapter, but also in the discussion chapter, Chapter 8, in the latter part of this thesis.

Respondent validation, or member checking, is the process whereby the researcher's observations, representations and interpretations of experiences are checked with whom they concern for accuracy, adequacy and fairness (Simons, 2009). The reactions to the analyses of the study participants then become incorporated into the study findings (Mays and Pope, 2000). Whilst it is possible that processes associated to respondent validation and respondents' reactions to the emerging findings can help refine explanations (Barbour, 2001), this validation strategy is not without its limitations. Sandelowski (1993), for example, argued that researchers and respondents should not be expected to arrive at the same themes or categories as the researcher, with Angen (2000) later raising a similar notion, in that that respondents may not necessarily agree with the interpretations of the researcher. Thus, in the context of the current study, member checking could have been adopted with the various individuals the researcher interviewed. However, as this was an exploratory, collective case study and not an evaluation case study, such a strategy was considered less appropriate, as the purpose was not to fairly represent different interests and values, rather it was to ensure that a collective understanding of the experience of the process of transition with which the researcher was concerned could be generated (Simons, 2009). Furthermore, given that the realities explored in this study were

multiple and co-constructed through the dialogues and experiences (Angen, 2000), "there is no static truth to which the results of an interview can be compared" (Angen, 2000, p.383).

However, Willig (2001), also deems reflexivity important within the context of fostering validity in qualitative research, thus this was also adopted within the context of the current study. The next section, section 5.9.1, explicates the ways in which reflexivity proved crucial in ensuring validity in this study.

5.9.1 Reflexivity

Reflexivity requires researchers to constantly reflect, with some level of criticality, on decisions made throughout the entire research process, and, as such, is regarded as a fundamental feature of qualitative research (Avis, 2005). The aims of reflexivity, Finlay (2003) states, are to provide:

> *… a confessional account of methodology or as examining our own personal, possibly unconscious, reactions. It can mean exploring the dynamics of our researcher-researched relationship. Alternatively, it can focus more on how the research is co-constituted and socially situated, through offering a critique or through deconstructing pretences of established meanings.* (Finlay, 2003, p.16)

Holloway (2005) further builds on this view by stating that reflexivity has to address the interaction the researcher has with not only the research itself, but also the research participants, in addition to addressing the reciprocal nature of the relationship between the researcher and the process of inquiry. Reflexivity requires researchers to be self-aware, recognise power relationships between themselves and their participants, and acknowledge potential unexpected disclosures from participants and their own emotional responses during the research (Holloway, 2005). To meet these requirements, Giddings and Grant (2009) argue, a degree of self-reflexivity is required to ensure that the researcher's positioning in relation to the phenomenon under study is explicit. The qualitative researcher is, in fact, a central

figure in the construction, collection, selection and interpretation of data (Finlay, 2003). Thus, a researcher's reflexive account is most notable through the incorporation of their personal thoughts and feelings into the research writings (Gough, 2003).

Therefore, the researcher maintained a reflexive journal throughout the entire research process. This journal served a dual purpose; it facilitated the recording of personal reflections and helped ensure transparency throughout the research process, as advocated by Ortlipp (2008).

In terms of personal reflections, the diary allowed the researcher to explore these on an ongoing basis, but particularly so prior to and immediately following the interviews. However, the use of the diary to reflect on the data collection activities in their entirety was especially important, particularly so as the researcher was able to reflect on her pre-understandings, beliefs and values about the phenomenon of transition that she was concerned with (Giddings and Grant, 2009). In addition, the diary provided a forum in which the researcher could 'critically reflect' (Holloway 2005) on an event or action and capture her reflections and thinking about such an event or action after it had taken place. Indeed, such reflections frequently emerged within the context of conducting the interviews, particularly so those with the young people and parents. At times, the researcher found it hard to remain dislocated from their experiences. The emotion embedded within many of these interview interactions was such that, at times, she felt a sense of guilt almost, that it was her role that had re-ignited these emotions for some of the young people and parents in this study. However, on other occasions, the researcher was reassured that her role as an interviewer and the experience of participating in an interview had brought a sense of purpose and meaning to some participants, akin to the positioning of Fine (2003) referred to previously. In addition, some participants appeared to find their involvement in the research interviews to be therapeutic in some way, as recognised by Dickson-Swift and colleagues (2006) in their consideration of similarities and differences between research and therapy interviews. This duality of the interview

experience tempered some of the researcher's reflections on data collection, as the following extract from her reflective diary illustrates:

> *… just to note what the TYA I interviewed told me when I called him to check he was feeling okay after the interview – he said that he felt that he had gained something from participating too – he had felt better for actually talking about some of the things that had gone on in the past and concerns re fertility, so he was really appreciative of the opportunity to talk about it. I did say that sometimes it helps to talk about things to a neutral/independent person, who isn't a friend or family or knows any of the previous history of what has gone on before. So to know this is how he felt was quite reassuring and demonstrates what benefit these interviews can have ...* (Lisa McCann, Reflexive diary, 19/01/11)

In terms of methodological transparency, the necessity of the use of the reflective diary was again evident. As discussions in section 5.10 will demonstrate, following some initial pilot study work, some amendments were required to the study. The reflective diary was a particularly powerful mechanism to not only record potential amendments arising as a consequence of the pilot work, but also as a way in which methodological transparency during these iterative developments to the study could be assured.

Finally, the researcher found the use of her reflective diary to be a particularly powerful tool during recruitment, as here she reflected on some of the challenges associated with recruiting in a hospital environment. At times the researcher struggled with the overt and covert duality of having a presence at the paediatric or adult hospitals. That is, whilst it was necessary that her collaborating clinicians knew she was there, clinic arrangements were such that not everybody either knew who she was, or indeed needed to know, despite her wearing of University identification during all recruitment activities. An extract from the researcher's reflexive diary captured during a recruitment visit to a paediatric hospital was particularly illustrative of some of the challenges posed by recruiting in such a busy environment:

> *The area is incredibly busy – goodness knows how many different clinics are on in just this area today. It is absolutely bonkers! I've tried to look for [CNS name] and [Consultant name] a couple of times by poking my head down the corridor but couldn't see them. Once the desk cleared of people trying to check in, I managed to grab one of the nurses to ask if [CNS name] and [Consultant name] were about. [Consultant name] was in the corridor at this point – so I let him know I was here and where I was sitting. I've had to sit on a row of chairs to the left of the main clinic desk – so I'm not sitting right in amongst all the parents and children but just to the side on a row of four chairs – rest are empty at the moment […] As I seem to be sitting in the main thoroughfare corridor to all the different areas of outpatients, I seem to be getting a lot of looks and glances from people as I sit here and write. People probably wonder who I am/what I am doing. I just hope that because [CNS name] isn't here and I'm not immediately visible to [Consultant name] that he remembers I'm here …*
> (Lisa McCann, Reflexive diary, 17/03/11)

Shortly after writing this extract the researcher was indeed able to gain the attention of her collaborating Consultant, with the successful recruitment of one young person as a result of this clinic attendance. However, the researcher's experience at this particular clinic allowed her to consider her positioning as a researcher in this environment, as, although she had tried to appear as discreet as possible within the clinics, people, both those she spoke to and others with whom she had no contact, became acutely aware of her presence there. The researcher's presence appeared to intrigue some people, as she was, on occasion, asked if she was the social worker. However, telling them she was a researcher there to try and recruit patients was enough to settle the curiosity of most that approached her.

5.10 Pilot Study

As indicated previously in this chapter, in the current study a pilot study was conducted prior to moving to the main study. Conducting a pilot study has a number of distinct advantages, including: the opportunity to develop and test the adequacy of

research instruments; opportunities to assess the proposed approaches to recruitment and their likely success; consideration of whether or not the chosen sampling frame is appropriate; and the collection of preliminary data (van Teijlingen and Hundley, 2002). It is argued by van Teijlingen and Hundley (2002) that, although the conducting of a pilot study does not always guarantee success in the main study, it is still an essential element of good study design.

It was outlined previously in section 5.3 that, initially, the current study proposed to conduct repeated interviews with the same young people prior to and following their first appointment in the adult sector. The recruitment strategy was dictated by the clinic attendance arrangements for these individuals; as they would have technically left the paediatric hospital and not yet attended the adult hospital, young people were to be recruited via letter invitation from the Consultant Oncologists or Consultant Haematologists at the adult hospital. Further, the letter-based invitation via the consultants was selected as the primary route for recruitment due to ethical constraints of gaining access to potential participants' contact details. That is, the researcher was not permitted access to young people's contact details until they had consented for her to have this information. Thus, young people were asked to return a 'consent to participate' form that they were sent with their letter of invitation directly to the researcher to allow her to make follow-up contact and recruit participants willing to participate.

During the pilot study, a total of four participants were recruited and interviewed: two young people and two parents. Analysis framework processes were also piloted, with a number of central themes identified, permitting tentative descriptions of the experience of transition for these participants. Thus, the pilot study was considered successful within the context of this study.

However, following the pilot study and the successful recruitment of these first two participants, it subsequently became increasingly challenging to recruit patients. During a 4-month recruitment period, no young people were successfully recruited, despite 12 young people being invited to participate. It became evident that the

implemented recruitment strategy was limited, despite numerous mechanisms to help ensure its success. Such mechanisms included providing recruitment logs to the consultants, following-up any potential leads with the consultants on a weekly basis, and contacting the consultants to ask them to issue a reminder letter to young people.

Patient numbers were therefore evidently regarded ineffective and recruitment problematic. Numerous reasons for the lack of success of this recruitment strategy could be postulated, such as young people not reading the information they received, or young people not appreciating the importance of replying promptly to an invitation, or recruitment not featuring as a priority task for consultants, despite initial assurances they were willing to take this responsibility on board. Alternatively, it may have been possible that young people did not wish to participate in the study.

However, as it was difficult to draw any definitive conclusions on the reasons for the recruitment challenges experienced, detailed and candid discussions with the supervisory team and clinical collaborators about the difficulties encountered and the implications this posed suggested it was clear that an amended approach to recruitment and the study design was required in order to ensure success of the study. Consequently, amended ethical approval was sought for two substantial and one minor amendment. Firstly, in terms of study design, in a departure from the initial approach of recruiting one group of individuals to be interviewed at two time points, two groups of individuals were instead to be recruited. These young people would be interviewed once, but the study would still capture the experiences at two distinct stages of the transition process by recruiting young people who had either just had their last long-term follow-up appointment at the paediatric hospital or their first long-term follow-up appointment at the adult hospital. Secondly, the recruitment strategy was amended to move from letter-based to face-to-face invitations. Thus, approval was granted to permit the researcher's attendance at the outpatient long-term follow-up clinic appointments at both the paediatric and adult hospitals. This strategy allowed the researcher to introduce herself, provide study information and obtain contact details from young people with their consent to allow the researcher to follow-up the study invite no less than 24 hours following this initial introduction. Such

introductions, however, only occurred with those young people who provided verbal consent to their consultant oncologist/haematologist during their consultation that they would be willing to meet the researcher, as it was the HCP who first raised the study on the researcher's behalf during the consultation. Finally, as a minor amendment, to further aid successful recruitment in light of these substantial changes, a second paediatric hospital was added as a study site, as mentioned previously in section 5.4.1.

Thus, following approval for the changes outlined previously, a further short period of pilot work was initiated, to ensure both the revised recruitment strategy and amended interview topic guides were considered appropriate. Consequently, Case 01 was recruited and interviews conducted accordingly. The gathered data from Case 01 were subjected to intensive examination by the supervisory team, prior to piloting the analytic framework on this data. Such processes were particularly beneficial as they highlighted that no significant changes were required to the recruitment strategy, the interviewing approach or the case note reviews. This method reflected the iterative developments made prior to this stage of pilot work, so it was considered appropriate to include Case 01 within the main study. Thus, the study continued; approaches to recruitment and data collection progressed as per the processes and procedures outlined throughout this chapter.

5.11 Chapter summary

This chapter has reported the methods adopted for this study, including an overview of the study aim and research question, sample, ethical issues, methods of data collection and the analytic procedures adopted to ensure the aim of the study and the research question were addressed. The chapter has also outlined some of the pilot work which was conducted and the iterative developments incorporated into the main study as a result of some of the challenges experienced during this phase. In the next two chapters, Chapters 6 and 7, the findings of this study are reported.

Chapter 6 Introduction to the results chapters

6.1 Introduction

The current chapter and the chapter that follows present the results of this study. Chapter 6 first provides an overview of the conceptual developments in this study, prior to providing an overview of the study population and an introduction to and overview of each case recruited. This is followed by a summary of the study results, by way of introducing and describing the orienting theme and the associated main and sub-themes identified in this thesis. This discussion 'sets the scene' for Chapter 7, in which the main orienting theme identified in this study, namely, 'The experience of readiness in the context of transition', and the supporting themes are discussed fully.

6.2 Conceptual developments

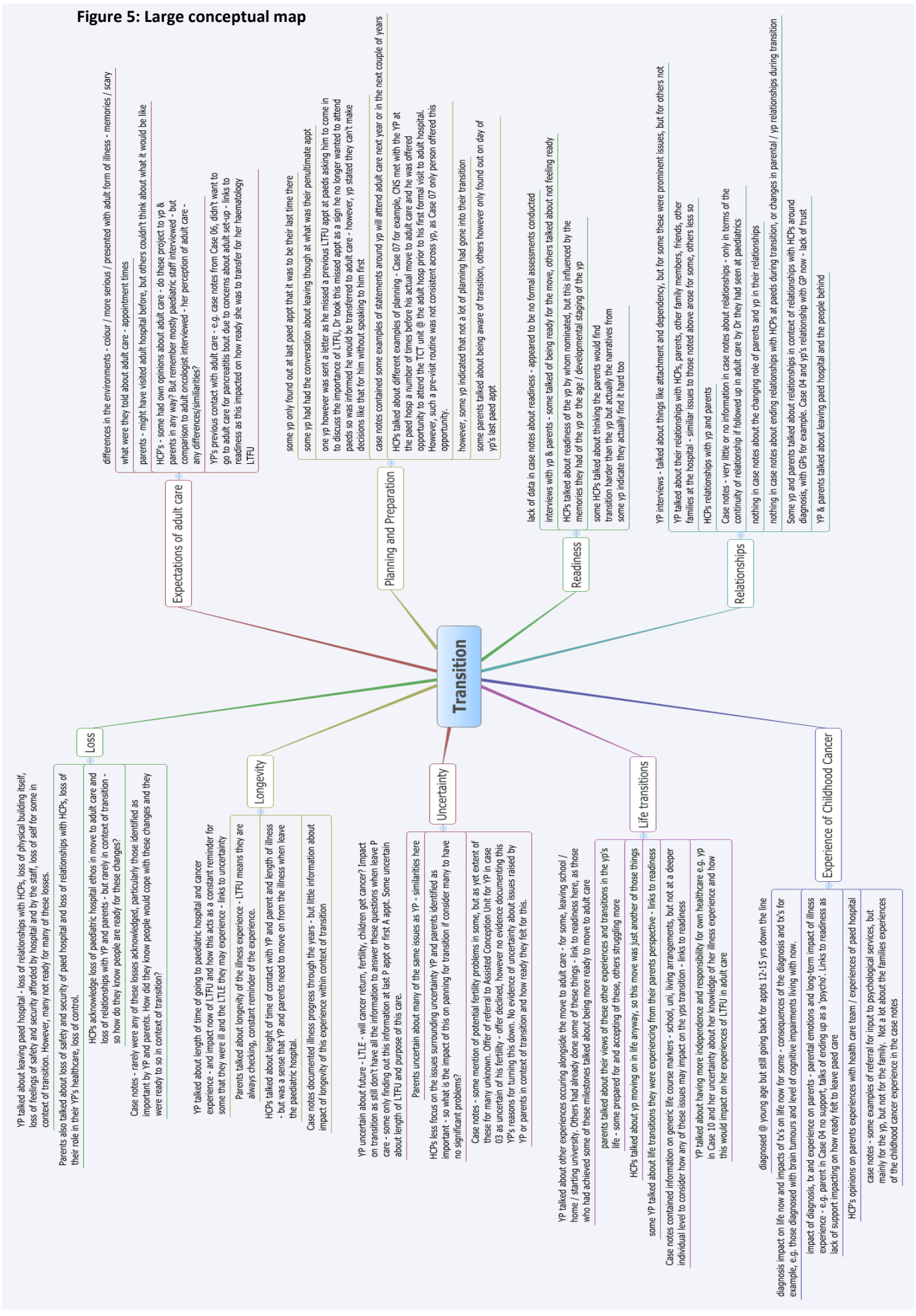
6.2.1 Making good sense: Contrasting and comparing

For Miles and Huberman (1994), making good sense of the data is crucial to permit the drawing and verification of conclusions. These authors propose one range of tactics that permits the generation of meaning from the data and another which tests and confirms those meanings. As such, in the current study, a tactic was required that would allow the researcher to conceptually investigate the data by contrasting and comparing the evidence from multiple perspectives, to sharpen her understanding (Miles and Huberman, 1994) of what was occurring. The contrasting and comparing tactic in this sense was considered the most viable within the context of the current study as the cases as a whole could be compared and conclusions tested (Miles and Huberman, 1994, p.254).

To do this, the researcher returned to the completed role-ordered matrices previously discussed on pages 157-160 and the original list of identified sub-themes. A conceptual map (see Figure 5 on page 172) was then developed, with each of the main themes plotted as appropriate. For each of the main themes identified, the researcher ensured that the data represented the multiple perspectives considered in this study

to investigate and verify the identification of the themes and sub-themes. Structuring the data through a conceptual map such as this ensured relations between issues and comparisons between the different sources were visually available for the entire data set, thereby ensuring the cases as a whole were compared and contrasted, akin to the recommendations of Miles and Huberman (1994). Throughout this process the researcher was aware of any crossover and linkages between the key themes, but by examining the data at an explanatory level like this, the results were comparable with what else was known about these cases (Miles and Huberman, 1994). Figure 5 illustrates this process and the emergent links and crossovers between themes which led to the subsequent stage for drawing meaning from the data – that in which conceptual coherence was sought, as discussed in section 6.2.2 that follows.

Figure 5: Large conceptual map



6.2.2 Making good sense: Making conceptual coherence

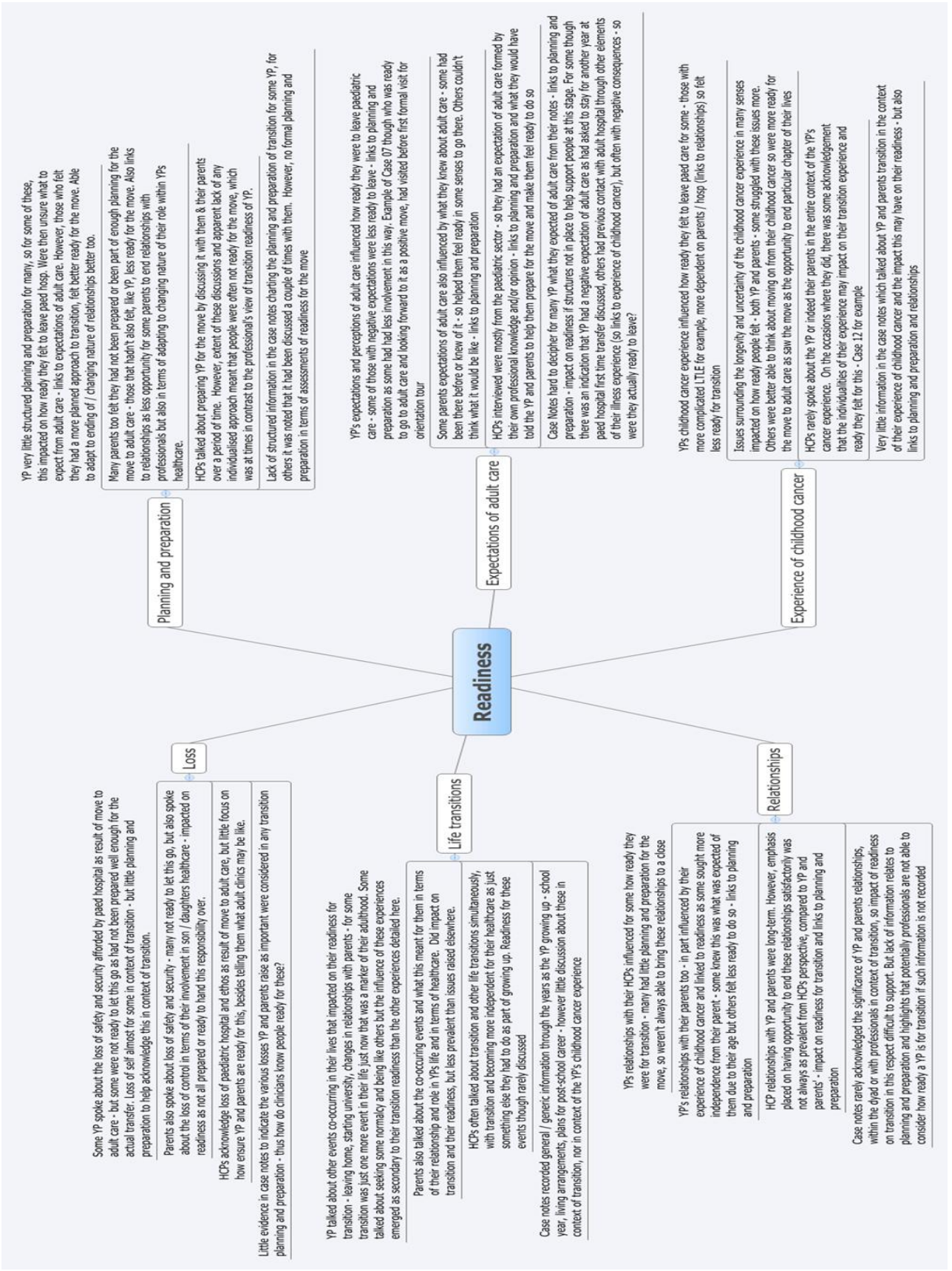
To ensure conceptual coherence in this study, the researcher sought to move in a transparent way from the raw data, to descriptive understandings, to interpretive explanations of the experiences of the participants in this study, by inductively deriving a number of categories from the data. To aid this process, a series of conceptual maps were developed, as illustrated previously in Figure 5 on page 172 and in forthcoming Figures 6 and 7 on pages 175 and 178, respectively. To create these maps, the researcher first drew on condensed data in the data reduction processes, to investigate the condensed descriptive data at the level of these higher order descriptive themes. Following the development of this conceptual map as illustrated in Figure 5, it was evident that yet a further tactic was required to permit movement from the observed interrelationships to a construct which would account for the 'how' and 'why' of the phenomena of the experience of transition under study (Miles and Huberman, 1994).

During consideration of the linkages between the data in Figure 5, it became evident that the 'how' and 'why' of the phenomena was emerging. More specifically, by considering a reoccurring theme within and between the data, it became clear that much of the data indicated that readiness was at the core of people's experiences of transition. In order to investigate this emergent concept and its explanatory power in the context of the data, particularly its influence on a number of the central themes previously identified, a further conceptual map was created to allow detailed consideration of its conceptual weighting. At this point, the linkages between readiness and these other themes were evident. However, prior to drawing any confident conclusions on the explanatory power of readiness for the multiple perspective experiences in this study, a further level of conceptual investigation was required to explore these patterns.

To do this, a second conceptual map was created. Here, readiness was placed as the central construct of the map to help understand if there were any differences in the levels of the other key themes identified. Again, as with the first conceptual map, discussion was conceptualised for the multiple perspectives in order to explain why

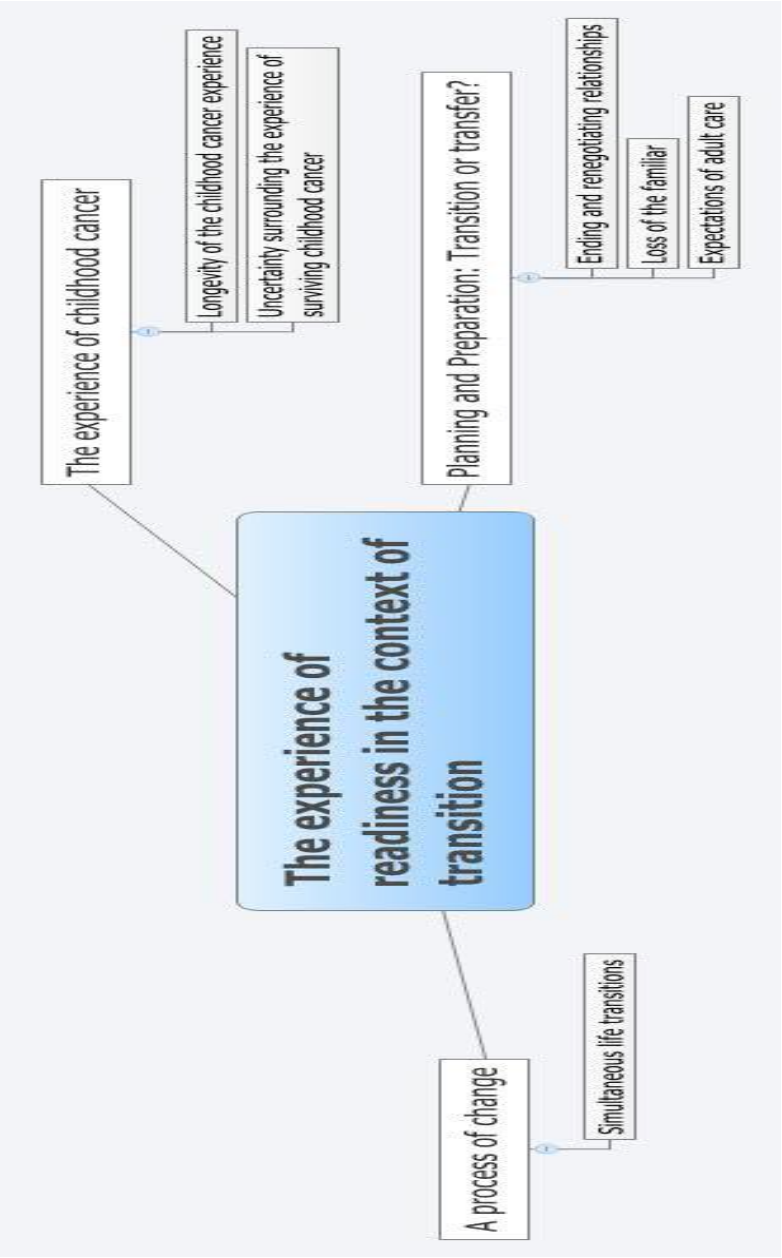
the patterns associated to readiness occur. Furthermore, investigating the data in this way allowed the construct of readiness to be related back to the cases to help explain the associated experiences (Miles and Huberman, 1994). This second conceptual map is illustrated in Figure 6 on page 175.

Figure 6: Second conceptual map



In-depth investigation of Figure 6 highlighted a number of linkages and overlaps between the themes and evidence. Thus, themes were collapsed to reflect the primary (main-theme) and secondary (sub-theme) levels of conceptual coherence derived from the interpretations of the data. Such interpretations ensured that the findings were empirically grounded in the data (Miles and Huberman, 1994) and linked appropriately to the corresponding construct. One final conceptual map was then created to ensure these themes had been condensed appropriately and to maintain the conceptual coherence. Thus, Figure 7 on page 177 provided the basis on which the movement towards conclusion-drawing and verification was assured in this study.

Figure 7: Final conceptual map



6.2.3 Conclusion-Drawing and Verification

Discussion throughout section 6.2 thus far indicates that progression through the stages of analysis were bottom-up, with movement from the raw data through to the concepts, with the final identification of a corresponding construct (Miles and Huberman, 1994). However, to ensure validity of the analyses and the identification of the central construct, the findings need to be tested and confirmed. It is essential the emergent meanings from the data are tested for their plausibility, and thus their validity to ensure their trustworthiness. Thus, similar to the approaches for generating meaning, Miles and Huberman (1994) propose a number of tactics for testing and confirming findings. Triangulation is one such tactic and, given the multiple perspective approach adopted throughout the study, was considered appropriate to examine the replication of the findings in this study. The multiple perspectives proved to be particularly important within the context of the conclusion-drawing and verification stages of analysis as they were particularly significant in terms of ensuring the validity of the identified central construct.

Indeed, at the conclusion-drawing and verification stages, investigation of the evidence from the role-ordered matrices and conceptual maps ensured the findings were replicated in other places, thus ensuring the validity and corroboration of that finding (Miles and Huberman, 1994). In addition, Figures 5 and 6 previously demonstrated the ways in which each theme had been investigated from the perspective of the different data sources. Thus, consideration of how well the findings of this study were supported, along with any potential inconsistencies and contradictions in these, was required to ensure conclusion-drawing and verification.

To do so, a matrix of findings by data sources and methods (Miles and Huberman, 1994) was created. Indeed, the power and value of adopting and maintaining a multiple perspective approach throughout this case study are demonstrated by not only this matrix, but so too by the findings in this case study. Certainly, embedding multiple perspectives in this study has certified that the facts of this case study have been supported by more than one source of evidence (Yin 2009). This matrix is

illustrated in Table 6 and provides a summary of the investigated data from the multiple perspectives for each theme and sub-theme.

Table 6: Illustration of investigation of data: Multiple perspectives

Orienting Theme READINESS	**EXAMPLES FROM INVESTIGATION OF MULTIPLE PERSPECTIVES**			
Explanatory Main Theme *Sub-theme*	**Young People Interviews**	**Parent Interviews**	**HCP Interviews**	**Case Notes**
The experience of childhood cancer				
The longevity of the childhood cancer experience	Complicated experience meant some were less ready to leave. Those ready to move on from their childhood cancer experience often also ready to move to adult care. Others struggled though – LTFU in adult care reminder of their experience.	Longevity of involvement in son/daughters care, some ready to move on from this experience, others found it hard due to extent of their involvement thus far.	Acknowledged length of childhood cancer experience, but often considered move to adult care as the opportunity to move on from this.	Inconsistent information in case notes about YP experiences of cancer – how to tell if were ready to leave paediatric care in this context?
Uncertainty surrounding the experience of childhood cancer survivorship	LTLE – questions surrounding their future fertility, cancer recurrence, their own children getting cancer, length and purpose of LTFU care. Some ready to move on from illness when leave paediatric care and therefore more ready for transition, but others find this harder due this uncertainty.	LTLE – recurrence of cancer, length and purpose of LTFU, future fertility. Constantly living with unknown, some ready to move on from illness experience when leave paediatric care, others struggle.	LTLE discussed, but rarely in same way as by YP and parents – HCPs think YP should be able to move on illness when leave paediatric care –but harder for some YP due to the uncertainty surrounding their future.	LTLE such as future fertility often mentioned, but rarely explored within context of an individuals' entire experience. How do they know if the uncertainty surrounding these issues influences YP transition readiness?

Planning and preparation: Transition or transfer?				
Ending and renegotiating relationships	Ending relationships with health professionals – some knew would be leaving so had opportunity to end these satisfactorily, others did not. Changing dynamics and roles within relationships with parents – move to adult care catalyst for change for some.	Ending relationships with health professionals – some knew would be leaving so had opportunity to end these satisfactorily, others did not. Changing dynamics and roles within relationships with son/daughter and their health care – move to adult care catalyst for change for some, but not all ready or prepared for these changes.	Ending relationships with young people and families – often considered a normal part of the childhood cancer experience – HCP's often more ready for this as know it is likely to happen at some stage. Contrasts to some YP and parents who found it a shock to leave and sad to leave people behind.	Nothing available in case notes to suggest either the ending of relationships or the renegotiation of these had been discussed in context of transition.
Loss of the familiar	Transition can mean the loss of safety and security of paediatric hospital and sense of self on occasion. Planning and preparation key to help ensure readiness to resolve these issues during transition.	Transition can mean the loss of safety and security and control. Planning and preparation key to help ensure readiness to resolve these issues during transition.	HCP's acknowledge moving involves leaving security of paediatric hospital behind – but how do they know if people are actually ready to do so?	No evidence to suggest loss of safety and security or control discussed in context of transition.
Expectations of adult care	For some fear, anxiety, negative, for others	Some aware of what adult hospital will be	Mostly paediatric staff interviewed, ethos of	Evidence variable – little evidence of individuality of patient experience

	excitement, positive move, ready to be treated like an adult.	like, others unsure.	adult care very different, did their opinions influence how ready some YP were for the change?	helping to address any concerns or negative expectations may have.
A process of change				
Simultaneous life transitions	Simultaneous changes – leaving home, starting university, changing nature of relationships and roles within these – those more ready for this, better transition experience.	Changes in other elements of YP lives and what this means for them as the parent – some accepting of these and ready for change, others less so.	Acknowledge other life transitions of young people, but rarely in context of entire illness experience and impact this may have on their transition.	Generic life course information – year at school, age, living arrangements, nothing to indicate ready or not for transition in context of these transitions.

Therefore, the findings from this study provide a detailed, multi-perspective and multi-layered depiction of the experience of transition of young people, parents, and health care professionals. This experience, as derived from the interview and case note data in this study, is explained by an orienting theme, 'The experience of readiness in the context of transition', which is supported by three main themes and six sub-themes, as illustrated in Table 7. Each main theme and its associated sub-themes are presented and examined in depth in the next chapter, Chapter 7, 'The experience of readiness in the context of transition'. However, within the current chapter, each main theme shall be introduced and the ways in which they were derived discussed. In forthcoming section 6.4 of this chapter, data are drawn from across the cases to demonstrate and support the identification of the orienting theme and each of the three main supporting themes, with Table 5 on pages 157-160 previously and Appendix 16 providing examples of full role-ordered matrices for Case 06 for reference purposes in this context. The sub-themes are considered in depth and detail in Chapter 7 that follows.

Table 7: Explanatory main themes and sub-themes derived from the data

Orienting theme	**Theme** *Sub-themes*
The experience of readiness in the context of transition	**The experience of childhood cancer** *Longevity of the childhood cancer experience* *Uncertainty surrounding the experience of childhood cancer survivorship* **Planning and preparation: Transition or transfer?** *Ending and renegotiating relationships* *Loss of the familiar* *Expectations of adult care* **A process of change** *Simultaneous life transitions*

6.3 Study population

In total, 12 out of 24 young people approached were recruited to this study between November 2010 and June 2011, resulting in 12 cases participating in the study. Each case consisted of a number of different individuals, so in total, 35 individuals participated. The sample included 12 young people, 12 self-nominated friends or family members and 11 self-nominated health professionals (one health care professional declined to participate). Furthermore, 22 sets of case notes were reviewed; 12 from the paediatric sector and 10 from the adult sector. Less adult than paediatric notes were reviewed as, on two occasions, no adult file was available for review. Six young people were recruited from the paediatric sector and six were recruited from the adult sector. The mean age of the young people recruited to the study was 18.25 years; there were 7 young men and 5 young women recruited and most young people had been diagnosed with Acute Lymphoblastic Leukaemia (ALL) during childhood. The mean age at the time of diagnosis was 6.75 years. All young people were long-term survivors of childhood cancer, at least five years from the point of diagnosis, and no longer receiving active cancer therapy treatments. Some young people were, however, taking hormonal or other medications as a consequence of the treatments they received in childhood. In terms of self-nominations, all young people nominated a parent as their friend or family member, with 11 mothers and 1 father interviewed. A variety of health care professionals were interviewed. Details of study participants are presented in Table 8 on page 186.

Participants were recruited from one paediatric hospital and one adult hospital in the west of Scotland and one paediatric hospital in the east of Scotland. The geographic range of hospitals was such that a range of rural and urban living locations were included. All young people self-nominated a friend or family member and a health care professional to participate in an interview. No friend or family member refused participation in the study, but on one occasion, the nominated health care professional declined participation. Young people and friends or family members of each case have been assigned a pseudonym. Health care professionals are identifiable by number only, to ensure anonymity. To further protect anonymity, nominated health care professionals have not been identified by job title, but it is notable that a range of

different professionals were nominated and included Consultant Paediatric Oncologists, CNSs, Clinic Assistants and Endocrinologists. Key characteristics of each case are illustrated in Table 8.

Table 8: Key characteristics of each case recruited

CASE	Pseudonyms/ Relationship	Age at Diagnosis / Age at Interview	Sector Interviewed	Nominated HCP Interviewed	Case Notes Reviewed Paediatric	Adult
01	Gary / Margaret Son / Mother	6 / 17	Paediatric	HCP 01	√	√
02	Mark / Wendy Son / Mother	6 / 18	Adult	HCP 02	√	√
03	Jordan / Liz Son / Mother	8 / 25	Adult	HCP 03	√	√
04	David / Patsy Son / Mother	4 / 18	Paediatric	HCP 04 Participation refused	√	√
05	Steven / Rosa Son / Mother	4 / 18	Adult	HCP 05	√	√
06	Sarah / Susan Daughter / Mother	10 / 17	Paediatric	HCP 06	√	√
07	Daniel / Morag Son / Mother	11 / 17	Adult	HCP 07	√	√
08	Jennifer / Anne Daughter / Mother	3 / 17	Adult	HCP 08	√	√
09	Martin / Helen Son & Mother	6 / 17	Paediatric	HCP 09	√	X
10	Kate / Peter Daughter / Father	11 months / 17	Paediatric	HCP 10	√	√
11	Carla / Fiona Daughter / Mother	11 / 19	Adult	HCP 11	√	√
12	Natalie / Sheila Daughter / Mother	11 / 19	Paediatric	HCP 12	√	X

6.3.1 Recruitment

Not all young people approached to participate in the study agreed to do so. Reasons for decline varied but included: scant memories of their childhood cancer experience; concern over nominating their mother to participate due to anxiety surrounding her emotional reaction to being involved; the opportunity leaving paediatric care afforded in terms of closing the chapter on the childhood cancer experience; or existing commitments. Two young people at the adult hospital were unable to wait to speak to the researcher at the time of their clinic attendance, thus provided their consent to the CNS to be sent study information in the post. However, neither were recruited successfully – each was contacted twice via telephone to discuss their potential involvement, but contact failed with both and neither returned the researcher's call upon leaving messages for them. It therefore became inappropriate to pursue these lines of enquiry any further after these two failed attempts.

A further 11 young people would have been eligible for participation in this study during the course of the period of recruitment, but for a number of reasons were not approached. Two young people declined to be introduced to the researcher at the clinic, a further five young people Did Not Attend their appointment and a further four asked to stay for at least one more year at the paediatric hospital during what was expected to be their last visit there.

6.3.2 Overview of the cases

Although Table 8 on page 186 outlined some of the key characteristics of the cases, a brief overview of each is now provided to allow some consideration of their wider context. Forthcoming discussions further introduce and firmly embed the cases within this thesis, thus, a brief synopsis of each case here is useful. As described previously in section 6.3, all young people nominated a parent as their friend or family member. Therefore, from this point forward for the remainder of the thesis, the term 'parent(s)' will be adopted to replace that of friend or family member, in recognition of the role of these individuals within the young people's lives.

Case 01: Gary, Margaret and HCP 01

Gary is a 17-year-old young man who was diagnosed when he was six years old and who received chemotherapy treatment. At the time of interview he was in his final year at school and was living at home with his family, where both interviews were conducted. Gary was approached following his last appointment at the paediatric hospital, which he attended with his mother. He nominated his mother, Margaret, to participate in an interview. For his health care professional nomination, Gary nominated HCP 01.

Case 02: Mark, Wendy and HCP 02

Mark is an 18-year-old young man who was diagnosed when he was six years old and who received chemotherapy treatment over a three-year period. He was approached alone in the adult sector following his first appointment there. His mother had attended with him but had remained in the waiting area throughout his consultation. At the time of the interview he was attending college and living at his family home, where both interviews were conducted. He nominated his mother, Wendy, for participation in interview. Mark also nominated HCP O2.

Case 03: Jordan, Liz and HCP 03

The eldest young man in the study at 25 years old at the time of interview, Jordan was diagnosed when he was eight years old. Jordan received a combination of treatments, such as chemotherapy and irradiation. At the time of interview, Jordan was living away from home in his own property. He had been independently managing his own health care since he was 17 years old. Despite being notably older than many of the other young people in the study, he had just attended the adult cancer setting for the first time when he was approached for participation. He had, in effect, been lost to long-term follow-up, and, had it not been for his own perseverance, would likely not have returned into the system. Jordan had transferred between hospitals and between NHS health board areas a number of years previously, with weaknesses in this transfer potentially contributing to the gaps in his long-term follow-up care. Although he had been independently managing his health care for some time, Jordan nominated his mother, Liz, to participate in an interview. Both Jordan and Liz were interviewed

individually in their own homes on the same day. Jordan elected to nominate HCP 03, from the first paediatric hospital he attended, to participate in an interview.

Case 04: David and Patsy

Diagnosed when he was four years old, David was 18 at the time of interview and received intensive chemotherapy treatment. He was approached at the paediatric hospital after his last appointment there, which he had attended on his own for the first time. He was living at the family home at the time of interview and nominated his mother, Patsy for interview. David nominated HCP 04 for interview. However, despite a lengthy liaison process with HCP 04's Secretary, this individual declined to participate in the study, thus no nominated health care professional interview was conducted for this case.

Case 05: Steven, Rosa and HCP 05

Steven was 18 at the time of interview. He had been diagnosed when he was four years old and received chemotherapy and cranial irradiation. Steven relapsed when he was 10 years old, which required him to receive further treatments. Steven was approached after his first appointment in the adult sector, which he attended with his mother, Rosa. Rosa was present during the entire consultation and was nominated by Steven to participate in the study. Steven was living at the family home, where the interviews were conducted, at the time of interview. Steven nominated HCP 05 for interview.

Case 06: Sarah, Susan and HCP 06

Sarah was 17 at the time of interview and approached following her last appointment at the paediatric setting. She was diagnosed when she was 10 years old and received chemotherapy treatment. Sarah's mum, Susan, attended this last paediatric appointment with her. Sarah was in her final year at school at the time of interview and was exploring various university options. She was living at the family home at the time of interview, but would potentially be leaving home if a university place so dictated. Sarah's health care professional nomination was HCP 06.

Case 07: Daniel, Morag and HCP 07

Daniel was 17 years old at the time of interview and had just attended the adult sector for the first time, which he attended with his mother and his aunt. Daniel was diagnosed aged 11. Daniel lives at the family home with his parents and his siblings and was due at the time of interview to imminently leave school, with a view to starting University after the summer break. Daniel nominated HCP 07, and his mother, Morag, to participate in the interviews.

Case 08: Jennifer, Anne and HCP 08

Aged 17 at interview, Jennifer was diagnosed when she was aged three and received chemotherapy treatment. Jennifer was approached following her first appointment at the adult hospital. Her mother was also present that day, although she was only present for part of her daughter's consultation. Jennifer was living at home with her parents and sibling at the time of interview. Jennifer elected to nominate her mother, Anne, and HCP 08 for interview (this was the same HCP Nominated by cases 01 and 05).

Case 09: Martin, Helen and HCP 09

Approached after his last appointment at the paediatric setting, Martin was 17 at the time of interview. He was diagnosed when he was four years of age. In terms of treatments, Martin had surgery and radiotherapy when first diagnosed and received further surgery when he was ten years old. Martin elected to nominate his mother, Helen, to participate in an interview. Both were interviewed, individually, at the family home on the same day. Martin also nominated HCP 09 to participate in an interview.

Case 10: Kate, Peter and HCP 10

Diagnosed when she was 11 months old, Kate was aged 17 at the time of interview and was interviewed following her last appointment at the paediatric sector. She had attended this appointment with her father and sister. Kate was living at home with her parents, but had plans to leave home and move to the city when she left school and turned 18. Kate had received both chemotherapy and cranial irradiation. Kate nominated HCP 10 for interview and her father, Peter.

Case 11: Carla, Fiona and HCP 11

Approached following her first appointment at the adult hospital, Carla was 19 at the time of interview. She was diagnosed when she was 11 years old, but unlike all the other young people in this study received no chemotherapy or radiotherapy treatment – she had surgical resection of the tumour alone. At the time of the interview, Carla was a university student and so the interview was conducted at her University Halls. She had attended this first adult appointment on her own, but nominated her mother, Fiona, to participate in an interview. Fiona was interviewed at the family home four days prior to Carla. Carla nominated HCP 11, who she had seen at both the paediatric and adult settings, to be interviewed.

Case 12: Natalie, Sheila and HCP 12

Natalie was 19 at the time of interview and lived at home with her mother and brother. She was diagnosed when she was 11 years old, for which she received radiotherapy, surgery and chemotherapy. Natalie's mother, Sheila, was present at the paediatric hospital when Natalie was approached; they had attended the entire consultation together. Natalie nominated her mother to participate in an interview and both were interviewed at the family home. Natalie nominated HCP 12 for interview (the same HCP nominated by Case 09).

Whilst concise, these introductions have permitted the reader to become acquainted with each of the 12 cases recruited to this study. The discourse in the remainder of this chapter and the findings chapter that follows explicates the findings of this thesis within and between these cases, ensuring greater cognisance of the depth of experiences of these 12 cases.

6.3.3 Situating the cases

The young person was placed at the centre of each case recruited in this study. However, to explicate and illustrate the concepts and themes within the summary of results in the next section of this chapter and throughout Chapter 7 that follows, the order in which data sources will be drawn on will vary. Such an approach will ensure a

rich portrayal of the experience of transition centralised in this thesis by revealing the multiple perspectives and realities so prioritised in this study. Such an approach is deemed to be beneficially illustrative of the similarities and differences within and between cases.

6.4 The experience of readiness in the context of transition

As illustrated in Tables 6 and 7, readiness was identified as the central orienting theme in the findings from this study, with such findings suggesting that understanding the experience of readiness is crucial in terms of understanding people's experiences of transition. This was particularly so as readiness was multi-dimensional in nature, so not only was it important to consider readiness within a context that reflected the individuality of people's experiences of transition, but so, too, the entirety of these experiences.

The orienting theme of 'The experience of readiness' is important in the context of the current study as this illustrates how transition should be considered within the context of young people's entire illness experience and the ways in which the multi-faceted elements of such an experience can impact on their transition readiness. The concept of readiness emerged in interviews with young people, parents and health care professionals, particularly in terms of the readiness associated to the actual physical transfer to the adult hospital. Whilst no evidence was available in the case notes to indicate that people's readiness was in any way formally assessed, available information did add to the level of understanding of this experience. Detailed investigations of the data illustrated that readiness for the physical transfer component of the transition process is bound by a range of associated experiences. These experiences, it can be deduced, can complicate or influence people's readiness for transition, thus the need exists for transition readiness to reflect the individuality of people's experiences.

As such, in this study, readiness was considered to have multiple facets, all of which influenced people's experiences of transition. For example, the findings illustrated

that participants' experiences of readiness were variable, as for some, their readiness was disrupted by the sudden onset of the physical move from paediatric to adult cancer care, whereas for others, such a move was regarded an inevitable next stage of their lives. Of interest, however, was the observation that within the cases, people's experiences of readiness were also idiosyncratic, resulting in individual constructions of their overall transition experience. Such an observation is exemplified by David and Patsy from Case 04. Here we see that for David, his forthcoming move to adult care involves little more than a move from one hospital to another, whereas for his mother Patsy, the move has shaken the foundations of her experiences at the paediatric hospital, both in terms of her involvement in David's care and the involvement of the paediatric hospital in their lives. A level of shock and hesitance about the move is therefore much more discernible in Patsy's narrative compared to David's, who seems better ready for the move by considering it in purely practical terms:

> *It, it dis'nae phase me. I'm no looking forward to it, and no 'no looking forward to it', it's just going to a new hospital … that's it.* (David, young person, Case 04)

> *… But I thought … just, had I known that would have been his last appointment I'd have said, "No, we need to make another yin,"… I was quite annoyed that I wisna there … that really kind of floored me … I know he's big enough and he's eighteen noo and it's aboot David but I would have … if I had ah known that was going to be the last appointment I'd ah wanted to be there … because we've always, I've always been there wi him and, so I was quite shocked when they got, I got back and he said, "No, the guy fae [adult hospital] was there and, that's me I'm going somewhere else," and I was like … "Oh my God!" [sounds shocked], because we'd been told, when David was 16 I had asked, "When does he go to an adult hospital?" and they said to me, "We'll keep David until he's in his twenties"…* (Patsy, mother, Case 04)

It is clear for Patsy that her readiness for the move to adult care has been influenced by information she received previously during David's experiences and contact with

the paediatric hospital. Such information led her to believe David would be attending the paediatric hospital for a number of years to come. Yet, it seemed from evidence within the case notes that David's likely move to the adult hospital had been raised in a consultation over two years prior to his actual last attendance at the paediatric hospital, in which an indication was given that David would leave the paediatric hospital at eighteen, not when he was in his twenties as revealed by Patsy:

> *I also explained to mum that we would continue to review David at the paediatric hospital until he is eighteen years of age when he will be referred to his local adult services.* (Paediatric case notes, Case 04)

However, it appears that information relayed at the clinic appointment to which the previous extract refers did not influence Patsy's construction of when she and David would leave the paediatric hospital. Although it is difficult to discern if the information reported in the case notes was fully reflective of the consultation, given the significant difference in ages reported between the two sources in terms of expected age of departure from paediatric care, it is important to note that the reality Patsy had constructed about a future move to adult care had undoubtedly been challenged by recent revelations that David's move was happening a lot sooner than she had initially anticipated.

As such, and of further interest in the context of these findings, are the ways in which the various complexities of the experience of readiness emerged both within and between cases, and the ways in which the three main themes identified in this study engendered the depth of understanding surrounding people's readiness in the context of their transition. The three main themes identified in this study, 'The experience of childhood cancer', 'Planning and preparation: transition or transfer?' and 'A process of change', are introduced in sections 6.4.1 to 6.4.3, with detailed and in-depth investigation of these themes and their associated sub-themes throughout Chapter 7 that follows.

6.4.1 The experience of childhood cancer

The main theme of 'The experience of childhood cancer' was identified as an a priori theme in the study, due to the very nature of the population being studied and the experiential focus of this study. However, by maintaining flexibility and adopting openness to the presence of the finer nuances and different emphases in the data (Bazeley, 2009), the significance of this theme was revealed. This a priori theme was supported across the data, with young people, parents and health care professionals frequently referring to this experience within their interviews. So too was this theme supported by young people's case notes, as this information reflected many aspects of their experience of childhood cancer, by documenting the various stages throughout their illness trajectory. In terms of young people and parent interviews particularly, prompts such as 'tell me what it was like when you (or your son or daughter) had cancer' were used to elicit an understanding of this experience from their perspective. Such prompts provoked a myriad of responses, encompassing experiences at the differing stages of the childhood cancer experience, such as the time of diagnosis, during treatment and the initial period of survivorship. Health care professionals, too, were asked what they recalled about the young person's experience of cancer, with varying levels of detail and information provided.

The main theme of 'The experience of childhood cancer' was considered to encompass a number of components regarded to have a significant influence on young people's and parents' readiness for transition, particularly so in terms of the extended and unsettled nature of this illness experience. For young people like Martin from Case 09, his experience of childhood cancer, and particularly so his experience of long-term late effects associated to his cancer and treatments, have been a particularly defining feature of his life over recent years, as detailed by his mother, Helen:

> *He's been left with horrendous disabilities that have taken seven years to fix, or six years to fix, whatever […] he's got co-ordination and motor problems, he's numb down the left side, so a bit like a stroke victim, so he doesn't feel as well with his hands and leg and his face, well, of course, the face crosses over so the right side of his face is numb compared to the left, so he's got a slightly, you can*

> *see when he's tired, his face can look slightly droopy, squint, so he's a bit like a stroke victim in that respect and he does forget about his left hand, like a stroke victim, "Will you use it?" … "Oh aye, I've got one of them", em he's got, he's had terrible problems with his vision, although, touch wood, it's not so bad now, but he had really bad double-vision and Nystagmus and horrendous eye problems, em, but he's had surgery and he also had Botox and stuff in his eyes and he now wears glasses and they seem to have got to a level that's quite good for him … and then he's completely deaf in one ear, and he's got partial hearing in the other, eh, so he's got that, and as I say, what else is there? God, there just seems to be everything [laughs] … every system. He used to have terrible incontinence but we've got over that, em, yeah so, I think we've just about had everything … and you see he was totally, he was in a wheelchair completely after the second surgery, couldn't see properly, couldn't hear [laughs] … was incontinent and so that's, it's almost like going back to having a baby … a b-i-g baby [laughs]. With a lot of work we've got him back to being independent, so I suppose we've got him to almost the stage now where we'd almost go, "He's eleven now, right we get on with it now," but he's going to have to go really quickly and become independent really quickly.* (Helen, mother, Case 09)

As Helen's narrative reveals, not only has Martin's experience of childhood cancer had a clear impact on him, but so, too, on her and her family, as the extent of his post-operative disabilities have been vast and multiple. This is particularly evident in her conceptualisation that given her son's experiences thus far, she would almost consider him to have the functioning of an eleven-year-old now, whereas, in fact, he is a lot older, so needs to accomplish some independence promptly. In addition, as further revealed in Helen's discourse, Martin's experiences of long-term late effects are such that she has had a significant role to play in his health care thus far, but given the stage he is at now – he recently attended the paediatric hospital for the last time – there is an onus on Martin to assume some responsibility and independence both for his own health care and for his own life more generally. However, Helen reveals elsewhere in her interview that she worries about Martin's ability to actually recognise if anything is wrong health-wise in the future and whether he would understand what would be

involved should any further problems arise. Such concerns, it may be considered, would influence Martin and Helen's experiences of readiness in the context of their experience of transition; particularly as Martin acknowledges the role his mother plays in his health care, with the approach to this very much dyadic in nature:

> *I live with it, you know I've got to live with the sight, the hearing, all that, em, so I kind of know what I can feel, if that makes sense, em, whereas my mum sort of, she has a different view which […] you know, it's what she sees, you know, she might see that I'm listening to the telly louder, or eh, and I'm sitting closer to it, 'cause I can't see it or something like that, and you know if she tells them something that I've not, or if I've hit on something that she's not, that's when they'll, you know they'll look into it.* (Martin, young person, Case 09)

Both Martin and Helen's narratives are indicative of the longevity of the experience of childhood cancer; an aspect recognisable amongst many other cases in this study. For someone like Martin, the meanings attached to this longevity may be saturated by the nature and extent of the long-term late effects the young person lives with, as some of these are permanent and irreversible, as reflected in Martin's case notes:

> *This lad has a combination of trunk and limb ataxia. I think the underlying causes are multifactorial. He has evidence of proprioceptive loss, he has evidence of vestibular loss and he has evidence of cerebellar loss of control. His scan shows small right cerebellar hemisphere. At this stage there are no interventions that are going to cure these problems. Almost certainly he is going to be left with this for the rest of his life.* (Paediatric case notes, Case 09)

From a transitional care perspective, Martin's nominated health care professional spoke of Martin's need to move to adult care to continue to receive his long-term follow-up care not only because of his age, but also because of his ongoing tumour and long-term late effect associated issues. However, there is a sense that little attention may have been paid to individual components of Martin's experience, as there is a

suggestion that, for someone like Martin, transfer to an adult equivalent service is more streamlined, and thus influential on the ease at which such an event can occur:

> *HCP 09: Because of the need for the fact that you know once you get too old for this hospital it's difficult and you still have ongoing things, requirements like scans or possibly procedures, you know you can't have them done here anymore, 'cause you're too old … so it's out of necessity because these patients still have needs and so this is for the neuro, neuro-oncology patients where it seems that the adult neuro-oncology service, 'cause they had a brain tumour may still have issues with regard to that, it seems the appropriate place to transition them to … so this is the easy part of transition for us. If you've had a kidney tumour there's no point going to an adult kidney tumour clinic, it just doesn't work … but going to see if you've got epilepsy or ataxia or endocrine deficit as a result of your treatment, that would be something that the adult neuro-oncology, neuro-endocrinology people are familiar in dealing with, so it's appropriate transition but if you've got ovarian failure as a result of abdominal radiation for your kidney tumour at the age of five, where would you transition that patient to? <u>More of a problem</u>. [original emphasis]*
>
> *Lisa: Mmm, and what happens in those situations just now then if somebody did need to …*
>
> *HCP 09: We're still following them up here [coughs]. And if they have a specific endocrine need then we would, we have em, em a gynaecologist reproductive medicine specialists who will look after them but we'll still see them here at [paediatric hospital].*
>
> *Lisa: M-mmm. So you might be seeing people of all varying ages …*
>
> *HCP 09: … Yeah …*
>
> *Lisa: … here at this stage? ...*
>
> *HCP 09: Yeah, I've, we've seen patients in their forties here. Mm-hmm.*

As identified throughout this exemplar data from Case 09, the openness referred to earlier during the investigation of the main theme of 'The experience of childhood cancer' revealed two prominent sub-themes associated to this experience. As

intimated in the data sources here, these sub-themes are: 'The longevity of the childhood cancer experience' and 'The uncertainty surrounding the experience of survivorship of childhood cancer'. Both of these sub-themes were considered to have a significant influence on young people's and parent's experiences of readiness in the context of transition; this will be depicted in the following chapter.

6.4.2 Planning and preparation: Transition or transfer?

The second main theme derived from the data, 'Planning and preparation: Transition or transfer?' arose as a key category due to the variability and variety of people's experiences of their move from paediatric to adult cancer services. The identification of such variability emerged as a positive consequence of the open approach adopted in the interviews, with young people and parents asked, 'What was it like to go to [paediatric/adult hospital] for the first/last time?' Later, targeted probing asked participants for their perspectives on the planning and preparation they had been engaged in the context of their move, with probes including, 'When did you find out you would be leaving [paediatric hospital]?' and 'What did they tell you about [adult hospital]?' Significant disparities between young people's experiences were identified in this regard. Some narratives were indicative of instances where the principles of transition as a process had been applied, as some suggested planning and preparation had been a key element of their transition experience. For others, though, no such structure existed. At times, planning and preparation was so fractured, the experiences of individuals in this study wavered between being considered a transition or a transfer. However, when examples of appropriate planning and preparation were noted in the findings, participants highlighted the benefits of having the opportunity to meet members of the adult oncology or haematology team prior to the departure from the paediatric hospital as a particularly positive aspect of their experience. Thus, such an opportunity quelled many of the anxieties young people or parents had about meeting a new member of staff in a new environment, thereby contributing to their readiness for a new attendance experience, as demonstrated by Rosa, the mother from Case 05:

> *And we met Dr [name] before … so he was not, we were not unfamiliar to him, and eh, that's why I, I didn't feel strange because he came a, a year before that to [paediatric hospital] and introduced himself and said … and I think he comes there also regularly so it was like em, just a change in the building for us …* (Rose, mother, Case 05)

Whilst Rosa's narrative is indicative of the duality of the transition experience, evident in her use of the terms "we" and "us" in the previous quote, narrative from Steven highlights that, for him, planning and preparation is important, not only in the context of knowing what the differences in environments would be like between paediatric and adult care, as reflected in Rosa's quote, but also in providing an opportunity for young people to avail themselves of the reality of further contact with cancer care services. Such a reality, Steven highlights, should be central to the planning and preparation people receive in the context of their transition to adult care:

> *They should make you, inform you that it's gonnae be for the rest, quite the rest oh your life this thing and like, inform you more about the future, which is the adult service, and they should tell you more about it when you actually get older, like fifteen, sixteen, like, I don't know, like, I don't know leaflets or what, I don't know … like, or hand-outs or that to, to actually explain what it's going to be like, rather than just, just tell you all of a sudden and like, to prepare you that this is going to be ongoing this, is going to be for the rest of your life … cause … just coming out of hospital you feel, it's finally over, then it's like stop, stopping it there, you have to do this, but in a whole different environment and it's going to be for the rest of your life, I feel you, you could get more aware of that …* (Steven, young person, Case 05)

Such findings, relative to Steven's quote above about the need to be prepared for the ongoing nature of long-term follow-up care and the experience of readiness in the context of transition, were further apparent at times when participants spoke in the wider context of their experience of childhood cancer, particularly so the longevity of this experience, as will be revealed in section 7.3.1 in Chapter 7 that follows. The

synergy between people's experience of childhood cancer and the planning and preparation surrounding their move to adult care appeared to be particularly influential on their experiences of readiness. In this regard, evidence in Steven's case notes was reflective of the processes of planning and preparation surrounding Steven's transition and eventual transfer to adult care, like that highlighted in Rosa's narrative, with noted introductions to the Young Adult Haematologist at the paediatric hospital and a home visit from the Young Adult CNS prior to his first attendance at the adult hospital. However, a Transition of Care summary plan contained within Steven's notes failed to reflect the elements of planning and preparation that Steven raised as being important in the context of his experience; the need for some awareness of the ongoing nature of long-term follow-up care in the adult setting.

Further findings in relation to the main theme of 'Planning and preparation: Transition or transfer?' were understood through three emergent sub-themes: 'Ending and renegotiating relationships, 'Loss of the familiar' and 'Expectations of adult care'. These sub-themes are explored in depth and detail in Chapter 7 that follows.

6.4.3 A process of change

The third main theme derived in this thesis is 'A process of change'. Although in some ways identifiable across the other themes, this theme particularly recognises the concurrent changes during a health care transition such as the one of concern in this thesis and the simultaneous life course transitions of young people and their parents. The sub-theme of 'Simultaneous life transitions' therefore pays particular homage to those other elements in young people and parent's lives and the way in which these were influential in many ways on people's experiences of readiness in the context of their transition experience.

This process is exemplified in the following series of quotes from Case 06. For Sarah, for example, her impending move to adult care, starting university, moving away from her childhood cancer experience and seeking some kind of normality, are complex

entities that, for her, are intertwined. However, it seems that her readiness to deal with these entities and their associated changes is limited in some respects.

> *Yeah, I think that moving on will make me, you know probably have to let it [her childhood cancer] go because … I just feel like it's not going to be about that anymore, it's about making sure that I'm healthy and you know proceeding being healthy, it's not going to be about that fact anymore. I just feel like it's just going to be more like making sure that it's not coming back and that I am, you know, getting on with my life and I think they'll probably push me more to let it go and push me more just to get on with my life and, you know, go to Uni and just live a totally normal life and not think about that, whereas I don't want to not think about it and just totally just … I don't know how to explain it but I just, I just know, feel like they will just treat me like I'm just, you know a normal person but … I don't really want to be treated like that because … it'd be … like I'm so used to being treated the way I am in [paediatric hospital] that I feel like, you know when I'm there I'm just a person that comes and goes every year…* (Sarah, young person, Case 06)

Whilst Sarah had her own concerns about the move to adult care and what this would mean for the way she was treated, her mother, Susan, expressed her own reservations about what the move would mean for her and her role within her daughter's health care. Although many young people sought some emancipation from their parents in the context of their movement to adult care and adulthood, some parents had particular concerns in honouring such developmental desires, particularly in light of the young person's cancer experience, as reflected in the following quote from Sarah's mother, Susan.

> *That's quite strange, 'cause obviously I've been a sort of a big part of her health care and looked, you know, been the main carer and always been there for her so, that will be quite strange that if I'm not em there at the consultations and she goes on her own and em, that will be quite, that will feel quite strange for me and I suppose a wee bit em … eh … empty's not the right word but, you*

know, em, a bit of eh … I suppose it's just another wee bit of growing up, isn't it? And leaving me, em … in a kind of, yeah, not having anything to do with it and being outwith my control … (Susan, mother, Case 06)

From a health care professional perspective, such life transitions were an extremely positive marker of success and survivorship, as the move to adult care offered a particularly poignant clinical indicator that young people were well enough to move on in life, as reflected in the quote from Sarah's nominated health care professional:

It's lovely to see them all, see them all em, you know out there just getting on with life and you know em, giving a, a … a very different emphasis you know, the, you know the world in general probably thinks, you know it's horrendous to have leukaemia … which in fact, you know, it obviously is at the time, but the fact that, you know, 90 or 95% of them are going to perfectly OK, that side isn't too often appreciated, but you never know the ones that … you just, because you never know the ones that aren't going to make it, it's em … no, it's lovely to see them all and just see them all getting on … growing up and being fine.
(HCP 06, nominated professional, Case 06)

Such positive markers of survivorship were also evident in many young people's case notes, with evidence to suggest consistent monitoring of young people through the years in the context of their schooling and family/living arrangements. However, although such information was positive in terms of providing indicators of young people's progress and the processes of change that mark their lives, very little evidence emerged from the case notes to suggest that the individuality of young people's experiences of these simultaneous life transitions had been considered, particularly so in terms of the context of their experience of the process of transition.

6.5 Chapter summary

This chapter has provided an overview of the cases recruited to this study, allowing the main orienting theme and the associated main and sub-themes derived in this study to

be introduced. The summary of results provided in this chapter provides the framework for a fuller explication of the findings in greater depth and detail in Chapter 7 that follows. In that chapter, each of the main themes introduced in this chapter – 'The experience of childhood cancer', 'Preparation and Planning: Transition or transfer?, and 'A process of change' – will be fully explored.

Chapter 7 The experience of readiness in the context of transition

7.1 Introduction

This chapter details the results which demonstrate the orienting theme 'The experience of readiness in the context of transition' by manner of the three main themes derived from this study. This chapter builds on the previous introduction to the results chapter, Chapter 6, by demonstrating the way in which the orienting theme pervades the data and the different data sources, thereby justifying its identification as the substantive theme from the findings of this study. The supremacy of this orienting theme is, however, further afforded within the current chapter by investigating each of the supporting main themes introduced previously in Chapter 6 in more depth and detail, and by explicating the findings associated with the sub-themes allied to each main theme. The first section of this chapter, section 7.1, therefore focuses on the orienting theme of 'The experience of readiness in the context of transition', whereas section 7.2 introduces the first of the main themes, 'The experience of childhood cancer'; section 7.3 focuses on the second main theme, 'Planning and preparation: transition or transfer?' and section 7.4 discusses the third main theme of 'A process of change'. This chapter closes with a summary of the overall study findings.

7.2 The experience of readiness in the context of transition

The experience of readiness in the context of transition was identified as the predominant and orienting theme in the findings in this study. Experiential discourse and case note data revealed that the experience of readiness was a central issue in the context of the experience of the process of transition of young people, parents, health care professionals and recorded clinical information, and, as such, can be justifiably located as the central construct in the findings from this study.

The experience of readiness in the context of transition was introduced previously in Chapter 6, section 6.4, with the multi-faceted components of this readiness demonstrated through drawing on one case exemplar, in keeping with the consistent approach adopted throughout the findings chapters. However, to further demonstrate

the power of this substantive and orienting theme, in the current section, data exemplars will be drawn from a variety of cases, to illustrate the ways in which this theme persists throughout the data. Sections 7.3, 7.4, and 7.5 will return to the adopted approach of Chapter 6, in that they provide multiple perspective data for each case.

The importance of understanding people's experiences of readiness emerged within the narratives of young people, especially as some implied not only how important being ready was for them, but also for other young people in a similar situation. Gary from Case 01, for example, was someone who felt that leaving the paediatric hospital was par for the course in terms of his experience and his personal situation, although he did acknowledge that although this was a potentially sad time, the direct impact of attending the paediatric hospital on him personally over the last few years has been minimal, so it required less of a personal renegotiation for him. In turn, he acknowledged that he was ready to make the transfer to the adult setting, particularly now within the context of his illness experience and having had the opportunity to meet the Doctor from the adult hospital on a number of occasions at the paediatric hospital:

> *Gary: A bit sad really, to be leaving, but sort oh … not bothered, it doesn't really affect me very much any more, I just thought, I go up there every year and, just to get checked out and it doesn't really … I doesn't really bother me, I'll go tae wherever, it doesn't really bother me to move to an adult clinic that much ...*
>
> *Lisa: Mm-hmm*
>
> *Gary: … it's a different place, basically, different things going on but … really I'm ready for the change ...*

Here, we sense that Gary believes his move to adult care is not something particularly anxiety-provoking; rather it is something he is ready for, especially within the wider context of his illness experience. It can therefore be inferred that because Gary believes his experience of cancer in childhood to have less of an impact on his life now,

he is more assured in his belief of his readiness for the move to adult cancer care. Further, for someone like Gary, for whom their illness experience has shaped and influenced their experience of readiness, rather than dictated it, there is a sense that this readiness is very much a positive facet of their overall experience of transition. In contrast, for some other young people, like Natalie from Case 12 for example, there was a sense that achieving a comparable level of readiness to Gary was some way off, despite having recently attended the paediatric setting for the last time. It seems that for Natalie, discussions about a potential future move to the adult sector had been mooted previously, yet these conversations and the ensuing delay to her transfer did little to actually dissipate her doubts surrounding this move, thereby negatively impacting on her transition readiness:

> *Yeah, like ages ago, a few years ago they used to tell me that I would maybe have to go over to [adult hospital], but then because I wanted to stay at [paediatric hospital] they let me, because I know everybody and that, and I didn't want tae, so they let me but because I've had aw that time I'm a bit more used, got used to the idea but I still dinnae really want tae move.* (Natalie, young person, Case 12)

The experience of readiness was also particularly apparent within the parents' narratives. Not only were parents' discourses revelatory in terms of affording an insight into the impact of leaving the boundaries and significance associated with the paediatric hospital on their experience of readiness, but they were also indicative of an awareness that, as a dyad, a departure from the paediatric environment was, in all actuality, sometimes considered timely. The timeous readiness for this move was, however, often driven by the age and physicality of their son or daughter compared to other children and young people in the waiting room. Thus, there was a sense that as a dyad, they should be moving on from the paediatric environment. However, despite such awareness, the move to adult care still came as somewhat of a shock to some parents and young people, especially to those for whom there was a notable lack of structured and definitive transition planning and preparation. The quote below from Helen, the mother from Case 09, illustrates this point. Helen believed her son Martin

was ready to leave the paediatric hospital as he was “just too big” to be there, but not knowing exactly when he would be leaving did little to ensure she was ready for the event when it actually occurred:

> *It’d be nice to just … prepare’s not the word, what's the one I'm looking for? Just, to know in advance that that’s what's happening, not just like, you're sitting there, “Right, this is it,” “Oh, right, OK” [laughs] … 'cause most places, you know when you're leaving …* (Helen, mother, Case 09)

As Helen’s narrative above indicates, it seems that she and Martin were given very little structured information about the move to adult care, which did little to foster their awareness about when the physical transfer from paediatric to adult cancer care would actually occur. It was, therefore, apparent within the narratives of many young people and parents that the experience of readiness was penetrated by the planning and preparation that surrounded their transition.

It was also apparent within the data that, at times, the centrality of readiness that was particularly influential on the experiences of the process of transition from young people and their parent’s perspectives was not always clinically comparable, particularly so from the perspective of the case notes. As raised previously in Chapter 6, section 6.4, no evidence existed within young people’s case notes to suggest their transition readiness had been in any way formally assessed. This was true for young people for whom a Transition of Care Summary document was located within their case notes and for those for whom no such a document existed. Yet, in the cases where a Transition of Care Summary document was identified, information contained within this often did little to suggest a young person’s transition readiness, within the context of their wider experiences, both illness and developmental-related, had actually been considered. Thus, it was difficult to discern how these components had influenced the planning and preparation that surrounded their actual move to adult care and how this information was reflected in the constructed transition of care summary document. An example of this discord was particularly evident within the case notes of Jordan from Case 03. As the extract below from his case note indicates,

and is was revealed previously in the introduction to Case 03 on page 188, Jordan had been 'lost' to long-term follow-up for a number of years, prior to his recent first attendance at the adult hospital. However, the components of Jordan's experiences that had led to and were reflected in his transition planning are difficult to decipher from his Transition of Care Summary document, as the plan for transition section in this document was blank. Instead, details were completed for more medically-orientated information, such as his medical history (diagnosis, date of onset, decimal age, endocrine investigations, and imaging), and more generic demographic information (name, address, date of birth, consultant, age, height, weight, and BMI). Thus, it would seem that although this document was passed from the paediatric to the adult consultant during Jordan's recent transfer of care, the information relayed was primarily medical in nature and failed to reflect Jordan's illness experiences and his experiences within the paediatric setting and why he had perhaps been lost to follow-up for such a long time:

> *It is probably more appropriate that Jordan is seen in the Adult Services, rather than a paediatric setting […] I enclose a copy of his referral from [original paediatric hospital]. Unfortunately he was last seen in [paediatric hospital transferred to] almost 10 years ago. I enclose a copy of his Adolescent Transition Summary*. (Paediatric Case Notes, Case 03)

Thus, young people's case notes rarely explicitly detailed the ways in which they were deemed ready for transition and the actual transfer between paediatric and adult cancer care, aside from their chronological age. Yet, this information, in combination with the narratives of young people, parents and health care professionals, proved particularly vital in developing an understanding of the experience of readiness in the context of transition, particularly as its paucity was in many ways demonstrative of the need to better understand this phenomenon from an experiential perspective.

As indicated above, the notion of readiness was, at times, discernible in some of the nominated health care professional narratives, as it was implied that if a young person's move to adult care had been planned in some way, this positively contributed

to young people's and parents' readiness for making the actual transfer from the paediatric to the adult hospital. However, as young people's and parents' narratives revealed, there was a lack of consistency in terms of the planning and preparation surrounding the move from paediatric to adult care across the cases. So, although the following quote from HCP 07 illustrates the benefits of a planned approach, data revealed that the reality of the experience of readiness from the perspective of young people and parents was at times incongruent with that of health care professionals' perspectives:

> *I mean, normally they would begin to introduce the fact that at some point in the not too distant future we have to start thinking about moving into adult services and explaining the reason behind that in terms of em, you know, being involved in adult services for all other aspects of their health, em, so that was all discussed and I spoke to mum and I think his aunt and Daniel at the time and then saw them again the next time they came, they came back and they understood that that was likely to be their last visit, so they had a while to contemplate what it was going to be like.* (HCP 07, Case 07)

As implied within this quote from HCP 07, prior and early introduction to the reality of an impending move from paediatric to adult cancer care was critical in terms of fostering Daniel and his mother's readiness for leaving the paediatric hospital, particularly so as they had time to assimilate this information into their lives. However, as will be revealed throughout this chapter, such an opportunity was not afforded to all young people and parents, thus the importance of understanding individuals' experiences of readiness in the context of transition was once again revealed.

Thus, as the data extract exemplars in this section have demonstrated, the experience of readiness in the context of transition permeated all of the data and provided an appropriate orienting construct for the findings of this study. The explanatory power of this orienting theme is further demonstrated throughout this chapter in sections 7.3 – 7.5 that follow, by manner of three main themes that emerged from the data: 'The

experience of childhood cancer'; 'Planning and preparation: transition or transfer?'; and 'A process of change'.

7.3 The experience of childhood cancer

The experience of childhood cancer permeated not only the narratives of young people, parents and health care professionals, but also the evidence available within young people's case notes. People's experiences were variable, which meant they often assimilated the dimensions of their experiences in their own unique way. Such individuality proved crucial in attempting to understand people's experience of readiness in the context of transition, as their experiences of this readiness were also diverse. The individualities of people's experiences of childhood cancer were understood through two sub-themes: 'The longevity of the childhood cancer experience' and 'Uncertainty surrounding the experience of childhood cancer'.

7.3.1 The longevity of the childhood cancer experience

Participants' narratives revealed that their experiences of childhood cancer were permeated by the longevity of the experience. For the majority of young people in this study, cancer was diagnosed very early into their childhood. As a consequence, this experience was a very prominent feature within their lives, and indeed the lives of their parents, for many years. Such was the durability of their experience; it was particularly influential on people's experiences of readiness. Indeed, it was the longevity that emerged within many people's narratives as being a central defining feature of their experience of childhood cancer. Such longevity was considered to be particularly influential, either positively or negatively, in regards to people's experiences of readiness within the context of transition.

In a positive sense, the transition experience offered some young people a promising opportunity to gain some closure on their childhood cancer experience, as the movement to the adult sector signalled the end to this period of their life. Indeed, some young people appeared ready to move on in many ways from the aspects of their lives permeated by the experience of childhood cancer. The anticipated change

of focus of the long-term follow-up appointments in the adult sector seemed to influence this in many ways for some, particularly if there was an expectation that the new approach would prioritise issues of importance to the young person within not only their present context but so too their future context, rather than an enduring focus on what happened to them in the past. Seeking some assurance of being considered as an adult survivor of childhood cancer within the context of his move to adult care was important to Gary from Case 01. His desire to obtain some level of closure on his childhood cancer experience was apparent in much of his dialogue:

> Gary: *… but Dr [name]'s been really … so, "How is it actually affecting <u>you</u>, [original emphasis] as a person in life?" rather than just what's medically wrong with you, which I feel is kinda more appropriate now because it doesn't, the medical side of it's a bit kinda outdated a bit … since it's been a long time. I don't feel it's as relevant.*
>
> *Lisa: And how do you think you'll be treated in, at [adult hospital]?*
>
> *Gary: More, more kinda, as a, as person that's, a young adult rather than a child, more as a person that's sort of been through it and has come out the other side rather than somebody that's, has the possibility that they could get it again, so … like a little less formally and kinda or kinda uptight about results and things …*

The desire and expectation that he would be treated not only as an individual, but also as someone who had survived the childhood cancer experience, drove, in many senses, Gary's ability to consider the longevity of his illness experience as a positive aspect of his readiness for transition. His prior contact with his new consultant from the adult hospital, coupled with his experience of an alternative approach to his long-term follow-up consultation whilst still at the paediatric hospital was a positive experience for Gary. This experience can be considered in the context of later findings in section 7.4 of this chapter, in which the differences planning and preparation can make to people's experiences of readiness in the context of transition, are revealed. For Gary, this planning, together with the closure he sought on his experience of childhood cancer, in many ways fostered his readiness for this particular stage of his

illness experience. In some senses, Gary's feelings were echoed by his mother Margaret, as she, too, appears to assimilate the move to the adult hospital as an opportunity to move beyond the boundaries of a unit which has only served, in many ways, to exacerbate the longevity of their experience:

> *I think [adult hospital] probably will have less impact on us both because it's not, you know, it's not going up to see if something … it's just a, a follow-up and it's not going back to the same place … cause this is a, a different clinic and this is a, for a different, well it's not for a different reason, I don't really mean that but, it's not that, it's not got the same links to the unit.* (Margaret, mother, Case 01)

There is a sense in both Gary and Margaret's quotes that moving to adult care was a positive experience and one they both appeared ready for in light of the opportunity it would afford in terms of leaving some of those early childhood cancer experiences behind. The positivity surrounding Gary's transition was also evident in the narrative of his nominated health care professional, HCP 01. Although her memories surrounding Gary's transition experience were somewhat vague, she did recall a consultation in which the notion of a move to adult care was first raised. Her experience of this led her to consider Gary to be ready to move on from paediatric to adult care, with his reaction to this news and his physical size core indicators of this readiness from her perspective at this time:

> *I honestly can't remember … em, I don't remember there being a problem with Gary, I don't remember him being upset, em I do think he looked ready, he's a big, eh, healthy-looking boy and under normal circumstances he would be fit to, to move on … I mean, I don't remember any major traumas for him or any, em, heartbreak in the situation, but … em … [laughs] … but I think he was ready to move on, and I think eh, even if I felt that they were being eh, if they, if they were upset I would still feel that that's not a reason to prolong the agony, you know, the break has to occur and they have to, to do it …* (HCP 01, Case 01)

There is a sense in HCP 01's quote that had there been any emotional indication from Gary that the prospect of moving to adult care was challenging, the move would have continued regardless, with perhaps some disregard for the root of any anxiety. However, there is a sense from all three participants in this case that the move to adult care was a positive experience, although little evidence was actually available in Gary's case notes to reflect this. No adolescent transition of care summary sheet was available within Gary's case notes so very little information was available to indicate the ways in which the move to adult care and what it represented to Gary had been discussed within those clinical interactions. Yet, despite his desire to move on from his childhood cancer experience, it seems that the tests Gary will have during his first appointment at the adult hospital may actually reinforce the longevity of his experience, particularly as one such test will be unique for him within the context of his long-term follow-up care. However, the case notes did not provide any detail on Gary's perspectives of the prospects of these tests:

> *We plan now to transition him to the adult centre and his next appointment will be at [adult hospital] in one year's time. At his first clinic visit there we will do routine bloods and arrange a follow-up echo as I cannot see that he has had one performed since completing treatment. He is also aware that he will be referred to our Clinical Nurse Specialist.* (Paediatric case notes, Case 01)

The individuality surrounding the longevity of the experience of childhood cancer was apparent within the twelve cases in this study. Some young people, like Gary in Case 01, saw the move to adult care to be positive as it offered a way in which he could move on from his illness experience, but still ensure his future health needs were met. However, on occasion, other young people like David in Case 04 were indifferent about the move to adult care. David particularly saw this merely as a continuation of what happened in paediatric care, but only in a different hospital. Such indifference could have been considered an indication of David's readiness to move on from the paediatric hospital, yet there was a sense that some bravado surrounded much of the narrative in his interview. Analysis suggested that such bravado may have manifested from a series of boundaries David erected during his experience of childhood cancer,

as it appears he has very rarely, if ever, engaged in any discussions with his health care team about his experience of childhood cancer, despite having lived with this for 14 years at the time of his interview. Such a decision appears to have been borne from the lack of opportunity he considers he has had to explore the complexities of his experience in the paediatric environment:

> *Lisa: And was it something that the doctors were aware of that you, you know, if they were asking you, you know, how do you feel about this or X, Y, Z … and you, you know, you were saying, "I don't want to talk about it," did they ever try to explore that with you a bit more?*
>
> *David: I didn't, obviously, I didn't want to talk about it, they've never really asked me aboot how I feel, so … I coudna tell them anyway so I'd probably just tell them a lie, which I wid … a complete lie aboot it if they asked me aboot my feelings, I'd just be like that, "I'm fine," which I feel fine aw the time, but I don't know, what annoys me, just as I says, I build them aw up … so, and then I forget aboot them …*
>
> *Lisa: And if you're at this stage now thinking about, you've met Dr [name], and you're going to [adult hospital], if you've got things you want to discuss with him that you've been building up, would you feel happy to do that at your next …*
>
> *David: Naw, I'd just lie to him and tell him I'm awright the day … aye, I wid, I'll tell you that the now even if he asks me I'll … he'll be like that, "How do you feel? Have you got anything you need to talk about? Is there anything going on bad or something?" I'd probably, if, if there, probably wis I'd ah forgot aboot it anyway, 'cause I forget everything and I'd, ah just lied to him. I just lie like that, "Naw, I'm awright, honestly, I'm fine …"*

In the previous quote from David, in addition to his overt statement that he would lie about his well-being to his health care professional team, and specifically, to his new consultant when he goes to adult care, there is a sense that he is aware that at times he does need some support, with those consultations affording an opportunity to seek this. However, his reluctance to address any of those issues in this forum means the

coping style he has adopted is likely to prevail in adult care. David's hesitance to reveal any insight into his experiences in his consultations suggests that his readiness to move on from paediatric to adult cancer care was driven by his chronological age, and not within the entire context of the longevity of his individual experience. Indeed, the longevity of his experience appeared to be considered only in the context of the need for long-term follow-up care in his case notes, as reflected in the letter below which he received following a series of missed appointments:

> *I noticed that you have missed two appointments at the Late Effects of Leukaemia Clinic. We are keen to continue to meet people such as yourself who have been treated for leukaemia to ensure that you remain well and do not develop any problems in the future. These appointments only need to be once a year. I see that at your last visit, the Doctor that reviewed you discussed a transfer to the adult unit. This may be the explanation why you did not attend today. We have therefore arranged for a further appointment at [paediatric hospital] on [date and time] and I would be grateful if you could attend. We can then talk about the reason for long-term follow-up and sort out an appointment for you in the adult centre.* (Paediatric case notes, Case 04)

David duly attended his next scheduled appointment after receiving this letter and was told at that visit that his next consultation would be at the adult hospital. David had attended what transpired to be his last paediatric appointment on his own, as his mother, Patsy, was on holiday. In her interview, she described feeling "annoyed" by the fact she was not there at the last appointment. However, following her initial shock and disappointment with the way their departure from paediatric care had been managed, she appeared to assimilate the move as a positive experience, particularly as it afforded an opportunity to look forward to the next stages of her son's experience. For her, the fact her son no longer needed to be treated by the same people he had seen for the previous 14 years was reassuring:

Patsy: M-mmm. And as I said it's a, a step in the right direction. I'd rather be going to [adult hospital] than going back into [paediatric hospital] cause it's back …

Lisa: Is that important, then, to think about going forward and …

Patsy: Oh God, aye …

Lisa: … not going back?

Patsy: … aye, and that's my words to him, that's the very words I used when I was coming back fae Egypt, I says, "Well, you need to think about it like this David, it's a milestone, it's, you've moved on again, just getting better and better" and, the fact that, you know he was such a, there was so many grey areas wi him … "If they're letting me go, they must be like that - away yae go David, we don't …," you know, "There's nothing we can dae fur yae anymore," which is, so it's all good, and it's a good feeling.

As illustrated, for some like those in Cases 01 and 04, the longevity of the childhood cancer experience was a positive catalyst in the context of their experience of readiness as this longevity fostered people's readiness in many ways. The movement to adult care provided a welcome catalyst to achieve closure of and movement away from this element of their lives, positively influencing their overall transition experience.

Yet, for others, like Sarah and Susan from Case 06, the childhood cancer experience had pervaded their lives in such a way that their experience of readiness was, in many ways, complicated by the longevity of their childhood cancer experience. Sarah, in particular, appeared both unable and not yet ready to move on from her experience of childhood cancer. In many ways, this reluctance threatened her readiness for moving to adult care, as she was concerned that the longevity of her experience would not be recognised in adult care in the same way it was in paediatric care:

It's quite, it's quite sad 'cause like ... I have to go myself and, it kinda makes me realise that I'm not, you know, I'm not a wee, a wee child anymore and like, sometimes it's hard to like, obviously 'cause I've had [diagnosis]and I've went

> *through it and it is sometimes hard to believe that, you know I have and, but the fact that I'm better is quite upsetting because, I don't know how to explain it without sounding like a … like sound really stupid but, basically I, I seem to cling on to the fact that I had [diagnosis] and see the fact that I'm going to be moving on … I don't really want to let it go and if I'm going myself then you know, I probably will just let it go, but because it's been a big part of me I do try and hang on to it because before I was ill I was a totally different person than I am now, so I try and hang on to that because obviously it's changed me and then I'll be going myself and I'm kinda scared because I know that if I go to [adult hospital] myself then, you know I'll mature a lot more and I don't want to forget [paediatric hospital] or everything that happened to me but I know that, and if I go myself I'll just be going and being like, "Hi, I'm fine," get my blood taken and just leave and it'll just … I don't really want to go and do that because it means that I have to grow up and I probably do have to let it go.* (Sarah, young person, Case 06)

Being ready to let her cancer go was central to Sarah's experience, and this most certainly influenced her experience of readiness in the context of transition. Her experience of this can be further understood in the context of later findings of this thesis, particularly so in forthcoming section 7.4.2, in which loss of the familiar is discussed.

Nonetheless, for many parents, too, the childhood cancer experience was a protracted one, for they had supported and cared for their son or daughter throughout the whole experience. This was particularly true of Susan, Sarah's mother, as the childhood cancer experience was a particular defining feature of not only her and her daughter's lives, but so, too, her son's, as the desire to reach the point of being five years' clear determined all of their existence in many ways. However, for Susan, reaching this longed for point was not the ending to the experience she so craved, rather it became the beginning of a much longer experience, which only over time is she ready to address. The shock of reaching that five years' clear point and then immediately

moving to the reality of long-term survivorship and follow-up care is something which resonated with many of the parents in this study:

> *I do find, you know, if I do think, I try not to … I don't, I don't dwell on it 'cause I think you could go mad or you could get really upset and I don't want to, so … you know, that's quite sad, I think they're, they're, both* [son and daughter] *of them their childhood was kind of whipped away from them. Em, you know 'cause it was like … "Oh that's another, that's another year," [whispers], and I did think when she got to, well after 5 years that was it … em so, yeah, when it actually came to fruition that, you know, "You'll be checked for, for the rest of your life," I was like … "Oooh … oh, right … oh, she'll be checked for the …," yeah, I was a bit shocked so, em … but it's good, I mean, it's good that she's checked for the rest of her life and, and they said that gradually it'll get less and less and it'll be more like em … eh, eh questionnaires and things about how she's keeping, what she's like and how she's coping and, you know if, if there's anything happened to her, she had chemotherapy, just to help children in the future so they can reduce the chemotherapy for children or em change their em, the way they, they treat them which [is] good, em, and it is good that they are going to see her forever*. (Susan, mother, Case 06)

However, rarely was the longevity of the experience of childhood cancer reflected in young people's case notes with the same significance attributed within young people's and parents' narratives. In terms of Sarah's case notes, for example, little evidence was available to indicate that Sarah and Susan's perspectives on their concerns associated to the longevity of the experience had been discussed and the impact this may have on their readiness in the context of the process of transition to adult care. Within young people's case notes, the longevity focus, rather, was very much in terms of monitoring physical long-term late effects, and in Sarah's case particularly, monitoring acute episodes of her pancreatitis problems. Such was the significance of pancreatitis within the context of Sarah's extended childhood cancer experience, it featured prominently in the interview with her nominated health professional. Indeed, HCP 06 was aware and concerned about how this would continue to feature in

Sarah's life and how it would, in many ways, offer her a constant reminder of her experience of childhood cancer that perhaps other young people would not have to contend with:

> *She's got this added thing of this pancreatitis and it's always going to, you know, that's, that's quite em, debilitating and, or potentially debilitating, and hanging over her and the fact that, you know, everybody's going out clubbing and if Sarah drinks she knows what's going to happen to her, so, so em … in lots of ways that's … you know, she's not, she's not able to get away from it the same was as somebody else who's never had any of these side-effects or, and she's had that side-effect … you know from, during her maintenance chemo…* (HCP 06, Case 06)

As the highlighted examples from Case 06 indicate, the longevity of the childhood cancer experience is, in many senses, something which can complicate people's experiences of readiness in the context of transition. However, Sarah was not the only individual for whom the extended nature of the illness experience overtly threatened their readiness in the context of their transition. For some other young people, the very nature of long-term follow-up care, both in terms of its focus (on something that happened to them in childhood) and permanency (the care continues into adulthood and thus the adult sector), was particularly demonstrative of the longevity of the illness experience from their perspective. Some young people's narratives indicated that long-term follow-up appointments and contact with the hospital compounds this longevity, particularly so as engaging in and with these entities reinforces not only their role as a patient, but so, too, their identity as someone affected by cancer. For Steven from Case 05, for example, it seems the difficulties associated with the longevity of his childhood cancer experience and his actual transfer to adult care have only served to negatively epitomise this identity from his perspective. For Steven, such has been the impact of his childhood cancer experience; he believes his is a "life ruined". Interviewed after his first appointment in the adult sector, such a move seems only to have exacerbated the feelings of frustration and fragility that dominate the longevity of the childhood cancer experience from his perspective:

Steven: I don't know, just have to look at this, alright you're going to be going like, right now you're going to be going here for the rest of your life, kind of thing, and you just got out of one hospital and now you're thrown into another hospital and you're, you're just going to be … going to hospitals for the rest … well me, personally, just going to go to hospitals for the rest of ma life and being on medication, it's … I feel it's a life that's ruined, if you know what I mean.

Lisa: Why, why do you think it's a life that's ruined? Tell me about that.

Steven: Cause I'm, I'm tied down going to hospitals, hospital and, and taking medication, 'cause oh what's happened to me. It's not, I don't know, I just feel it's kind of unfair.

Lisa: Unfair?

Steven: U-huh.

Lisa: Tell me a little bit about that

Steven: What a … ?

Lisa: Why you think it's unfair.

Steven: I don't know … [slight pause] … cause it's, I don't know why it's unfair. I mean, I forget, just, it'll just, it'll, cause it'll never end, it'll be forever … [pause] …

Steven is struggling in many ways to come to terms with the longevity of his experience, yet the continuation of attending long-term follow-up appointments in a new environment has only added a level of complexity to this that he appears neither ready nor able to cope with at this stage. It seems that his feelings of being tied and bound to attending hospital appointments and taking medication threaten his experience of readiness in many senses. Although he had recently attended the adult hospital for the first time, such is the prominence of the longevity of the experience from his perspective, it seems he was not yet ready to accept the inevitability of this. Therefore, there is a sense that Steven's concerns about the permanence of his childhood cancer experience and hospital attendances appear to have disrupted his move to adult care. The fact he believes his experience will be "forever", may, in part,

be borne from the type of information he received throughout his transition experience, as he may have interpreted the information he received from his nominated health care professional as confirmatory to the assumptions he already held:

> *I mean I, I always have a kind of a talk last, last, last eh, visit talk where em, you know, I would put the pen down and talk I, I have a kind of formula that I run through and it's a formula because I don't want to miss anything out but, em, I will obviously, you know, be sympathetic to the age I'm speaking to so what you would say to, what I would say to them is, em, "You've had this chemotherapy and there's probably a very small increased risk of you having another type of cancer over your lifetime which could be, you know, 90 years," and I emphasize there's a very small risk and I say, I, I couldn't put a figure on it but it's probably no more than 2-5%, em, and children who've had radiotherapy it's probably a bit higher than that, so Steven having radiotherapy I would say that's something, that, that means that you have to be vigilant about any symptoms that persist or are unusual and, em, get them seen to, em, because a lot of things can be treated if they're picked up early …* (HCP 05, Case 05)

Although the latter part of the previous quote from HCP 05 indicates that some of Steven's illness experience was considered in the context of prioritising the need for continued and ongoing long-term follow-up, particularly as a result of his receiving radiotherapy as a child, there is a sense that chronological staging rather than any real individualized approach provides the contextual framework for this discussion. For example, HCP 05 talks about 'being sympathetic to the age' of the person she is speaking to in the context of discussing potential long-term late effects and the need for continued and ongoing long-term follow-up care. Thus, it seems such an approach tends to refer to chronological age and not an individualized approach, so it is possible to question how interactions such as these can ensure young people's needs are identified and addressed. The almost blanket approach to discussions such as these, as intimated by HCP 05, raises some questions over the ways in which the clinical team can readily identify what is important for young people. Moreover, based on the

previous quote from Steven, there is a need to consider what the interactions, like those outlined by HCP 05, mean for and to young people, as Steven's experience would suggest there is little opportunity to address these issues at an individual level in the context of the process of transition.

In contrast to Steven, his mother appeared, on the other hand, to be more accepting of the move to adult care, actually finding the experience of the first appointment in the adult sector to be a positive one. It seems Rosa considered this first appointment at the adult hospital to be an encouraging next stage in her son's illness experience, particularly as she observed some changes in her son's demeanour during that appointment. Although some of the struggles Steven has had as a result of his illness, treatments and other life event experiences and the resulting challenges these have posed for her as his mother were palpable in much of her narrative, observing her son interact with the new consultant at the first appointment in adult care was a reassuring indication that her son was making some tentative progress. However, this progress may yet be stilted by her concerns about Steven's readiness to fully manage these consultations on his own, as there is a sense she insisted on full inclusion in this consultation:

> *Rosa: And they said when we went there and he was very chatty and eh, which actually made me feel like "OK, we are, he's coming to the right part now," he probably has come out of this depressed state … and perhaps if I hadn't gone in, but I had to speak to the doctor, I perhaps would have never known it … so that was a good thing that I went in, and I came back actually very happy after that appointment.*
>
> *Lisa: Did you?*
>
> *Rosa: Mm-hmm, I was very happy …*
>
> *Lisa: Tell me a little bit more about that, why were you … why were you happy?*
>
> *Rosa: I was happy because, first of all, he's doing OK, they didn't put, and, eh, his health-wise they said was satisfactory and eh, to see my son more eh … what's I said … he talks more now, he and he, he doesn't hesitate to open*

> *up to people and probably he started trusting people and his doctors also, OK they are there to help … so that was something that I thought well that's good, that's a good positive change in my son.*

It was evident in Steven's case notes that his experience of childhood cancer has been both complex and prolonged, with input from various additional sources, such as psychological services, over the years. The extent of the challenges he faces were noted in correspondence following his first appointment at the adult hospital. However, although there was an intimation of both his mother's presence and his own progress, as demonstrated in the extract below, the issues surrounding the longevity of Steven's experience from his perspective, as revealed in his narrative earlier, are missing:

> *Steven attended the late effects clinic with his mother on [date]. This was his first visit to the Adult Late Effects clinic following referral from [paediatric hospital]. I note he suffered a number of complications of treatment including seizure activity, chronic viscospacial difficulty, social isolation, vitamin D deficiency, growth hormone deficiency and borderline testosterone. Despite these difficulties he is currently doing relatively well […] he has no current health concerns.* (Adult case notes, Case 05)

Continued hospital attendance, despite being many years from diagnosis and treatment completion, also compounded the longevity of the childhood cancer experience for Carla from Case 11. However, rather than feeling frustrated about this like Steven, Carla's narrative suggested that this continued attendance evoked a longevity to her childhood cancer experience that she struggled in some ways to assimilate, as she talked about the rarity with which her childhood cancer experience is now discussed with family and friends, as she believes this is something she has moved on from:

> *It kind of feels like I'm, I've moved on from it all now and, I guess that's why it feels really weird going to the hospital 'cause there's nothing wrong with me,*

> *but I guess it, just all that's in the past and whatever, just get on with … everything.* (Carla, young person, Case 11)

However, every year, her self-conceptualisation as someone who has nothing wrong with her is challenged by her attendance at her annual long-term follow-up appointment and the necessary return to hospital. Here she again becomes a person affected by cancer, with her recent first time attendance at the adult oncology centre offering a particularly stark reminder of this. Not only was she confronted with the longevity of her own illness experience, but so to the reality of cancer in adulthood:

> *It's weird because like, 'cause I was at [adult hospital] which is the cancer hospital it's, it's really strange because when I went I was like, it doesn't feel like I have cancer and I don't really, and I don't really have it anymore but I'm still here, but … eh … [laughs] … it was a bit strange, em, and looking around all the people thinking "Mmm?"… huh, there's quite a lot of people here you know, it's … a lot of people are just like myself … I guess it kind of feels … I don't know … nice in the sense that you're kind of with people that know what you're going through, I guess, well, what you've been through, but also it's kind of sad seeing all the people there as well that might have just been diagnosed or whatever.* (Carla, young person, Case 11)

Although Carla appeared somewhat taken aback by such prominent visibility of cancer in this new environment, she, too, found some comfort in knowing she shared a common experience with other individuals there. Whilst such visibility appeared to have little impact on her readiness to move to the adult sector, there is a sense Carla was perhaps unaware she would be confronted with people at different stages of their illness experience than she, as she appeared to struggle to assimilate this in some way within the context of her first appointment at adult care. However, her nominated health care professional, HCP 11, believed that Carla coped well with the new set-up during her inaugural attendance at the adult hospital, particularly in terms of those likely encounters with people with cancer of different ages and stages to Carla. The potential for this to be a distressing experience was acknowledged by HCP 11, but

there is a sense in the following quote that not only did Carla cope with these new experiences, but she was ready for this new approach to her health care:

> *My recollection is that she em … she had enough information to find the place which is always something, you know, "Can you, did you find your way here … did you manage to get here alright?" Em, that she felt comfortable in the waiting area which is em, better now than it was in that it's em … the area that we're using now is, all the people in that area are on long-term follow-up, although some of them are much older than her, so it's not people that are on active treatment, but she will have had to walk past areas with older people on, undergoing active cancer treatment, which can be distressing em … sometimes to them. Em, so she seemed to cope well with the sort of, set, set-up of a new clinic situation, which is, again, you're finding your way past the reception desk to the clinic area and then back to the reception desk to make your next appointment, em, and she was eh, comfortable enough in the clinic talking about just general things that we, we try and cover in that, that visit, so she, she came across as a … a confident individual who was, was happy discussing things rather than someone who was particularly anxious about it or … eh, worried about some health-related problem.* (HCP 11, Case 11)

It seems that HCP 11 considered Carla to have no anxieties about her first time attendance at adult care, but as earlier quotes from Carla demonstrated, this experience did encompass a level of anxiety for her, particularly as this attendance reinforced her role as someone affected by cancer and the longevity of her experience. However, it is possible that Carla elected not to discuss any of these concerns in the consultation, as it seems HCP 11 was unaware of how unsettling Carla found some elements of this first attendance. This disparity was further reflected in her case notes, as the only indication of Carla's experiences of this first appointment was captured in the overarching statement, *"In herself she is well".*

Although she did not attend the first appointment at the adult hospital with her daughter, Fiona's dialogue reveals the reality of the longevity of the childhood cancer

experience from her perspective. Fiona found the experience of having to wait for a telephone call from Carla following the appointment to be just as unsettling as her previous experiences of actually being there. However, on this occasion, the anxiety surrounding this experience appears to be heightened by the elimination of the immediate reassurance usually afforded by accompanying her daughter to the appointment and hearing information first hand:

> *Well, as I say, you know, be-, em just because of the whole, you know it, it, every time she has her annual check or appointments it's, it's so it, it brings back what happened at the actual time when it happened, obviously it, it was a stressful worrying time and it does kind of bring it back and I must admit … I was waiting for her to call to let me know how she got on and I had that horrible feeling that I remember only too well from nine years ago, you know you, you can't help but worry and you think, "Oh, maybe this time they'll find something," you know, but it's … as I say, obviously, from that point of view not being there and finding out straight away that everything was fine, you know, I'm sort of sitting here waiting for a phone call, but, that'll get easier, as I say, that was obviously it, it was probably quite hard for her and it was quite hard for me too, but, the next one won't be …* (Fiona, mother, Case 11)

There is a sense in this quote that although Fiona was aware of the feelings the annual appointments arise in her, she was in some senses unprepared for just how difficult she would find that initial experience of having to hear about the consultation second hand from Carla. Such unawareness, it could be cautiously inferred, has impacted on her readiness in the context of her transition experience, as, despite her acknowledgement elsewhere in her interview that Carla's independence and the move to adult care are part and parcel of Carla's development, the anxiety associated with this first experience has challenged this assumption. This experience can be further understood within the context of section 7.4 of this chapter, in which the need for appropriate planning and preparation for young people and parents is explored.

7.3.2 Uncertainty surrounding the experience of childhood cancer survivorship

The sub-theme of uncertainty arose in the interviews through questions and prompts which asked 'do you have any particular concerns for your health (or the health of [young person]) in the future?' Also, evidence surrounding long-term late effects and the impact of these on young people's lives was sought in the case note reviews. For many of the participants in this study, a sense of uncertainty particularly shrouded the survivorship experience, principally so in terms of the long-term late effects young people were living with now or may experience later in life. Dominating much of this uncertainty, in many senses, was the potential impact of these long-term late effects on young people's future health and well-being, with threats to future fertility and cancer recurrence commonly identified as key concerns, but for which, as yet, many answers were unavailable. However, this very same uncertainty defined the experience of childhood cancer in many ways for a number of participants.

It seemed for some that this uncertainty was only exacerbated by the manner and timing by which information was gleaned. For example, it was not unusual for some young people to be told at particularly distinctive stages of their transition experience of potential complications with their fertility, due to the treatments they received as a child for their cancer. It appeared for some that such a topic was only broached for the first time at either their last paediatric or first adult appointment, providing little opportunity for such information to be assimilated and incorporated within any transitional care planning and preparation. It further seemed rare for any assessments of young people's readiness or abilities to learn of such information to be considered, as no evidence existed in any of the case notes to suggest any kind of formal assessments of this nature were conducted. For example, Jennifer in Case 08, found herself confronted during her first adult appointment with information to suggest she may face fertility disruptions in the future. This was something she was barely prepared or ready for at that stage:

> *Jennifer: Em … aye, he brought up the, the discussion of fertility and he was saying, em, because I had chemo, eh, and obviously we were getting like, eh, lots of X-rays and obviously in-, invasive sort of treatment and all that sort*

oh thing, he was saying obviously there's, there might be like a, a less chance for me to be able to get pregnant later in the future and eh, menopause as well, I might start that early like late thirties, early forties as opposed to a lot of other people, and he was saying sort of, just talking me through that and saying, making sure I was like, okay with it and like, if I needed to talk to anyone about that, like if I was feeling really upset or anything about it, eh, making sure that I knew who I could go to and stuff like that.

LM: And how was it to hear that sort of information then for the first time?

Jennifer: Eh, well, obviously, you know, as a female, like, it's going to be a wee bit sort of take, taken aback, like, "O-h … right … OK," obviously, I'm only seventeen, so I'm not planning on running out and getting a family just now, so like, but you know, it's always something that you want to sort of keep open, never say never sort oh thing but eh … I don't know, I've sort oh just came up wi the thing where I was saying, if I, like well when I'm ready to have a family, obviously I'm going to try anyway 'cause it's not like they've said "Never, ever, ever – I can't have them," eh, obviously try and just see how things go, and it's just like a little hurdle that you get, sort of get over, you know what I mean? But obviously I was upset when they said, you know, like your chances are lowered because I mean, that's not really nice for anyone to hear especially as a, a teenager when I'm thinking ahead oh life, you know what I mean? But I mean … I don't know. I don't know if it's just me that's not really upset over it or what, but I mean, the way I look at it is there's plenty other options out there as well as if I can't have my own …

It is evident that Jennifer is grappling somewhat with this new information and the threats this may pose to her future health and planning, but by assimilating this information in the way she has, it is clear she is seeking some kind of positive resolution to this uncertainty. Indeed, uncertainty surrounding future health was not only a concern for young people, but so, too, their parents, particularly if they were also unaware of future complications their son or daughter may face. At times, parents spoke about seeking some reassurance about their son's or daughter's future

health at the time of diagnosis, with fertility featuring prominently in the context of these concerns, but they often spoke of having any such concerns or fears allayed at that time, thus such thoughts were discounted. However, for many parents in this study, their son or daughter had engaged in some level of conversation with the consultant about these issues, often either during their last paediatric or first adult appointment for the first time. Such conversations often meant not only were young people learning of new information, but so, too, were the parents. Many parents did not expect to hear such information now at this stage of their experience, particularly as some of the uncertainty surrounding their son's or daughter's future health was previously discounted, as illustrated by the following quote from Anne, Jennifer's mother:

> *… [Jennifer] told me later on like, you know that the doctor discussed certain things wi her and that, you know you sort oh think, "Oh, she is a wee adult now," you know, rather than just a wee kid, and also the things that he'd said, I mean, there was particularly three things that I didn't know about as well, you know, sort oh thing like, 'cause em, the likes oh eh, about her eggs and things like that and eh, that she might have a, lesser chance oh conceiving and all that, because that was the first question I asked when we were told at [paediatric hospital] – would she be able to have babies and it was, "Oh, yes, yes … ," you know, sort of, no problem there and eh, and then the other thing was the, there might be an early menopause that she might have as well, which I thought "Ooh?!" … you know, these are all quite serious things, you know, that had never been brought up in the 14 years and, what was the third thing? … em, [pause] … a higher risk oh melanoma with the sun and everything like that, now again I thought that should have been told to us, you know beforehand …* (Anne, mother, Case 08)

Health care professionals often discussed the potential and possible emergence of long-term late effects in the future for young people in this study, with some awareness of the uncertainty of any implications of these. However, it appeared that rarely the uncertainty surrounding the experience of surviving childhood cancer was

considered within the same context as young people's and parent's readiness for transition or indeed their readiness to hear new information at that particular stage of their experience. Rather, the focus was often on any specific or identified long-term late effect the young person was living with, but with little detailed investigation into how the young person felt about this. Furthermore, in Jennifer's case notes, the only indication that fertility had been discussed with her during her first appointment at the adult hospital was a late effects clinic pro-forma document, which had, under the endocrine section, a tick next to the question which asked if fertility was discussed. The box for expansive free-text was left blank. As earlier exemplar narrative from Jennifer illustrated, the uncertainty of this new information caused her some anxiety, but none of this, nor any assessments of her readiness to learn of such information, were captured in the clinical information.

In contrast to Jennifer, Jordan from Case 03 had been living with an awareness of potential problems with his fertility for approximately eight years at the time of interview. As will be illustrated in the section that follows, issues surrounding his fertility were a prominent feature of Jordan's experience of childhood cancer, particularly so the uncertainty surrounding his survivorship experience. During his interview, Jordan vividly recalled the exact consultation at the paediatric hospital where he learned he may face impaired fertility later in life; it was apparent the circumstances surrounding this consultation and the details of the actual interaction itself were very prominent in his memory and had shaped the way in which he had integrated such information into his life. Such an interaction, however, only arose as a result of Jordan's university education, as it was during an early period of his studies that he happened across information which discussed the potential for complications with fertility as a long-term late effect of childhood cancer. Jordan thus decided to raise and seek some clarification on this issue with his consultant at his next appointment, as he was at that stage unaware that any such conversations had occurred, in language he could understand certainly, to suggest that fertility would be a problem for him in the future:

> *I asked him and it was a really pretty, pretty horrid consultation and the worst thing about it was, of course, there was a consultant and he had, he always has, the consultant always had two or three people in with him, or I think this time he had about four folk in with him, and it was a really horrible moment, and it's something that I just think I, you know, nobody ever, nobody ever really sits down with you during the paediatric ones, well, certainly to me, maybe they did and maybe I was, didn't really know about it, and certainly they probably should have told my mother and father, nobody really tells you the complications then, you kinda have to educationally guess them yourself.* (Jordan, young person, Case 03)

This consultation occurred when Jordan was seventeen and it was the first he had attended alone. Although of a similar age to others in this study when confronted with such information for the first time, unlike many others, at the time of interview, he had been living with such information and the manner in which he heard it for eight years without ever really having his concerns or needs surrounding this issue addressed during any of his long-term follow-up consultations. But even now, following his first long-term follow-up appointment for many years, it seems such a pattern has continued, as Jordan talked about fertility only being raised briefly during his first consultation at the adult hospital. Despite the limited nature of this discussion, it did, however, appear from Jordan's perspective that although it was brief, such a discussion was actually a positive experience for him, as he was told at this time that his infertility was not one-hundred per cent confirmed. For Jordan, this was "*actually a nice surprise to actually hear that",* yet, from his case notes, it was difficult to discern if a deeper exploration and understanding of his experiences had formed a central part of this interaction. In all actuality, the level of detail surrounding this component of his consultation in his case notes suggests Jordan's reasons for refusing assessment at the Assisted Conception Unit had not been fully considered in the consultation:

> *He is not currently in a relationship, though we did discuss fertility. He is aware of the opportunity to be assessed at the Assisted Conception Unit, however has decided that he currently does not want to know.* (Adult Case Notes, Case 03)

Despite being offered the opportunity to have his fertility formally assessed, Jordan had, at this stage, declined such an offer. Whilst his case notes failed to provide any insight as to why this may be, it can be inferred that the extent of the impact of the missing support for Jordan in those intervening years since first learning of potential fertility problems is such that during that period, potential uncertainties with his fertility had manifested into a self-defined certainty – he now considers himself infertile. Although such a status is not clinically confirmed, the uncertainty of the impact of this on particular elements of his future is clearly revealed in the following quote:

> *It's difficult for me to say I've come to terms with it, because it's not an issue just now in my life, emm, fertility, and obviously, you know, I've not got any children at this moment in time whatever, so it's not something that I've, it's something right now that I'm fine with and happy in my head with, emm, but I don't know what's going to happen in the future if I come to a stage where emm, me or I have a partner might want children, what, what, their reaction might be or what they think about it, and that is, it's one of these, I think it's one of these things that until I'm put in that position I don't know how I'm going to feel, but at this moment in time, as far as I'm concerned I can't have children, that's as far as I'm concerned, that's it, it's very black and white …* (Jordan, young person, Case 03)

It is clear from these extracts that Jordan has grappled with the uncertainty surrounding his fertility and the impact of this on his future for some time, with such feelings seemingly magnified by both the manner in which he first learned of this information and his internalisation of these feelings over a number of years. From his nominated health care professional's perspective, there is a sense that Jordan's concerns regarding his fertility have come to the fore more as he has aged, with a

suggestion that concerns regarding fertility are often superseded by concerns of growth during adolescence; an immediately comparable outcome to peers:

> *Yeah, I mean, I think … you know, with, with, I mean, people like Jordan, and indeed Jordan specifically, obviously, as time went on there were particular health issues that were important to him so obviously, you know, progression through puberty which we had to help with, issues about, you know, fertility and indeed infertility given his eh, total body irradiation and the effect that has on, you know the, the testes and particularly, you know, the […] cells and germ cells, and you know the fact that you go through puberty spontaneously and although he did need a little bit of top-up of testosterone to take him fully through puberty, it is not a guarantee, of course, that you're going to be fertile because the, eh, you know, that aspect of testes function is much more sensitive to damage than the cells that produce the testosterone, so you know, obviously, when you're, you know, fourteen then perhaps your priorities and growth and development so that you're, you know, like your friends. Of course as you get older, then of course there are other things like fertility that become important and eh, you know, you tend perhaps then to perh-, you know, forget how important these other things were for you at the time, because they're not important anymore em, partly because you've done okay but even if you've done less well they still were not as important as they were when you were an adolescent and you know things that were important to adolescents obviously loom large and are not necessarily what's important to a younger child or a young adult.* (HCP 03, Case 03)

Of note is the fact that Jordan's fertility was not raised by his mother, Liz, during her interview. Her dialogue surrounding the uncertainty of her son's future health instead focused on the unknown entity of the long-term impact of the treatments in terms of their impact on his organ function. However, Jordan discussed in his interview how, following the consultation where he learned of potential fertility problems, his mother never again attended any long-term follow-up appointments with him, and he has only ever in passing briefly discussed the content or experience of that consultation with his

parents. It is possible, therefore, that Liz's narrative focused on her son's future health from the perspective of the known medical tests and screening that would be available to him, rather than any potential fertility problems, due to the self-imposed barriers Jordan created to protect himself, and perhaps others, from the reality of those discussions:

> *Oh, he was just told that, we were just told that he would need, you know, they'd need to monitor his heart because chemotherapy can damage, obviously, the heart and the liver and the, not the liver so much, the heart and the kidneys particularly and we were told that he would have to be on this follow-up, now they did the kidney function test once a year for years, he did, to be fair, but I felt kind of it all sort of dwindle around, off because Jordan seemed to be perfectly fine, you know and I think, you know as parent you just accept that because as far as your concerned your child's cured and I don't think maybe you really fully accept the long-term effects it can have, and I, and I think actually there's quite a lot of eh, even doctors themselves you don't, who aren't, they're still investigating the long-term effects.* (Liz, mother, Case 03)

The above findings have highlighted that young people's childhood cancer and survivorship experience is in many ways defined by the uncertainty that surrounds their future, particularly so in terms of their future fertility and health. This is significant in the context of people's experiences of readiness as many young people, and indeed their parents, had little opportunity to integrate such information into their lives prior to their physical move from one sector to another. Such integration was further hampered by the uncertainty of long-term follow-up care, as the findings demonstrated that people's understandings of the purpose and trajectory of this care were often limited.

Indeed, the reality of the trajectory of long-term follow-up care threatened Mark's and his mother Wendy's (Case 02) readiness for moving to adult care, as it seems it was never made explicit at any notable point throughout Mark's childhood cancer experience that his long-term follow-up care would necessitate a move of this nature.

From Wendy's perspective, the focus was very much on her son reaching the point of being considered "five years' clear", and never what happens in the longer term. Although she now subjects this construction to some questioning in the following quote, given her son has just newly attended adult care for the first time, we sense a real shock of learning his care would continue in the adult setting:

> *But once they'd finished, obviously, the chemo, it went to six months and then it went tae a year and the, they, they were always speaking once the chemo had finished this "five years' clear," so I don't know if it's maybe we've picked it up wrong … but we were always under the impression, that's the impression that we took again, as I say we could have picked it up wrong, em, but even when we were […] the Doctor was saying "well five year and that's us and,"… but naw, it wisnae, but, so maybe we picked it, we picked them up wrong but, I just thought after that we, I never ever thought for a minute that we'd be moving on to [adult hospital] … never. We were never under that impression ...*
> (Wendy, mother, Case 02)

Although Wendy doesn't articulate it here, it may be inferred that she expected Mark to no longer have to continue to attend any hospital appointments once he had finished with the paediatric hospital. Thus, her realisation that he would was tempered by the fact that not only would he have to do so, but also, if he would, he would have to do so in an adult hospital. However, evidence in Mark's case notes suggested that long-term follow-up care was likely to continue for some time, as there was an indication there that the likelihood of a move to adult care was raised at an appointment almost two years prior to his first appointment at the adult hospital:

> *We will see Mark again in one year's time [date] and if he has left school by then we will transfer him to the Adult Follow-up service at [adult hospital].*
> (Paediatric case notes, Case 02)

Similarly, Mark's narrative indicated that the inevitability of moving to adult care had been raised with him at the paediatric hospital previously, although it seems that his understanding and awareness of this appeared somewhat fractured:

> *They never ever really, I mean I don't, well, on the last couple of visits they might have said about [adult hospital], but they never says … they were saying I think we might, eh, think about, eh, transferring you to [adult hospital] and then but that was at my last, eh, two or three visits and then my last visit he says, eh, "We're going to transfer you to [adult hospital]," … [slight pause] … so, that was it.* (Mark, young person, Case 02)

7.4 Planning and preparation: Transition or transfer?

As detailed previously in Chapter 3 of this thesis, the definition of transition adopted in the current study is that proposed by Blum *et al.* (1993). Inherent within this definition is the need for appropriate planning and preparation for and during the transition process. However, as already suggested in some of the data in section 7.3 of this chapter and in Chapter 6 previously, young people's experiences of transition planning and preparation were variable. In the current section, a deeper understanding of people's experiences of planning and preparation is revealed by manner of the three emergent sub-themes: 'Ending and renegotiating relationships', 'Loss of the familiar' and 'Expectations of adult care'.

7.4.1 Ending and renegotiating relationships

The sub-theme of 'Ending and renegotiating relationships' illustrates the various relational changes that occur within the context of transition. Many similarities were observed between young people, parents and health care professionals in this regard, with the loss and renegotiation of relationships, both within the context of the health care professional team and the young person and parent dyads, offering a particularly poignant marker of the transition experience; some relationships came to an end, whereas others developed and evolved. Some changes were naturally occurring within the context of the young person's developmental staging, whereas others were

dictated by the physical move from paediatric to adult cancer care. However, young people's, parents' and health care professionals' readiness for these changes did vary somewhat and appeared, in many instances, to be associated with the processes of planning and preparation they had the opportunity to engage in.

In terms of the young people and parent dyads, there was some variability in the extent to which people were ready for the changes in the structure and roles in these relationships, particularly within the context of the young person's health care. Dyads such as Jennifer and Anne from Case 08, for example, were ready for this in many senses, with this having a positive impact on their overall transition experience as there was both some awareness and acceptance that they had reached a stage at which boundaries would be redrawn, some naturally so, and the positive impact this has on Jennifer in terms of her ongoing long-term follow-up care, as the following quotes from Jennifer and Anne illustrate:

> *I don't know, it just sort of makes you feel more grown up [going into the consultation on her own for the first time in adult hospital] when you're not having to have, like, your parents' permission all the time and like, having them take your hand and take you in and all that sort oh thing, it makes you feel sort of like, I don't know, I'm trying to find the words … like eh, well I guess just independent.* (Jennifer, young person, Case 08)

And, from Jennifer's mother, Anne:

> *I'm quite happy for her to go in and speak to them and whatever, I mean, she usually tells me everything anyhow that, you know, that goes on. Eh, but time will tell when she's, I mean she'll probably come to the stage where I won't be going in at all, I mean she'll just be doing it hersel, I'll just drop her off and she'll go in …* (Anne, mother, Case 08)

Whilst changes within the structure of dyads such as these may be considered to occur naturally within the context of young people's developmental transitions, documented

evidence in young people's case notes which accounted for any such changes was, however, scant. This is important to note, as not all young people and parents managed to renegotiate their relationship as fluidly or easily as Jennifer and Anne in the context of their transition experience, nor were all ready to do so. Yet, information on the individuality of these dyadic structures and any potential changes or indeed challenges to these prompted by the move to adult care were consistently lacking in the case notes. Despite the rareness with which such information was recorded, narrative from Jennifer's nominated health care professional, HCP 08, revealed that potential difficulties with young people and parents renegotiating their relationship in this context can be exacerbated by the parental-focused approach in paediatric care, particularly if a child is very young when first diagnosed. It seems such an approach induces the expectation of parents to be involved in all of their child's appointments, but as illustrated in previous quotes from Jennifer and Anne and the following quote from HCP 08, there comes a stage where these boundaries should be re-drawn. Yet, as recognised by HCP 08, the ease at which this can be done can, in part, be attributable to the nature of paediatric oncology care, in which the needs of both parties tend to be addressed on an ongoing basis:

> *You're dealing with a child at the very start who's maybe just in the very early sort of verbal stage, and so all of your, most of your consulting is through the parent, the child is there as a, you know, you're examining them physically, but most of the information you're getting is through the parent and that becomes a bit of a habit but, but also, em, all the anxiety is with the parents, not with the three-year-old with leukaemia, they don't give a … you know it's eh, so em, you do, as a paediatrician, you do, em … you do focus on the parental anxiety and the parental em, what's reported by the parent and em, it's not surprising that the parents, as they come to clinic have a sense of entitlement that you'll continue to address that, you know, at even fourteen years into the, eh, most parents are very good in, in thinking well, that's not appropriate anymore, they don't have leukaemia, but some em, still want to be able to sound off you a wee bit …* (HCP 08, Case 08)

The former part of this quote highlights the central role of parents in the paediatric oncology setting, with HCP 08 stating that the approach of addressing parents over young people in the consultations "becomes a bit of a habit". Whilst honest in such an acknowledgement, it does permit some consideration of the extent to which young people are provided with the opportunity to engage in independent consultations prior to moving to adult care, where there is a greater expectation these will occur. As a consequence, it further reinforces the need for appropriate planning and preparation during the process of transition, particularly as the renegotiation of relationships between young people and parents has been demonstrated to be a significant element of people's transition experiences.

However, for some young people, the reality of confronting a change in their health care and hospital attendance provoked some anxiety, particularly as having someone present with them at the appointments offered a level of security. Yet, for someone like Kate from Case 10, who was aware that her recent last appointment at the paediatric hospital would be just that, there was a sense that she was not yet ready to redraw some of the boundaries surrounding her relationship with her parents in the context of her health care. However, Kate does not live on the mainland, so it seems in some senses that financial arrangements may actually influence the redrawing of this boundary more than any personal desire to have this level of independence, as now she is an adult, a subsidised flight for a parent to accompany her to her appointments is no longer available:

> *Kate: When they told me like, "Oh, you'll be going to [adult hospital] after this appointment," and stuff, then they would tell me like all the, like all the … aaw [sighs], I can't remember the word, like all the wee things about it, I was a bit nervous like, like … "Oh no, what am I going to do when I go to a new hospital? I don't know anybody. I'll probably get lost," like walking round looking for nurses and stuff and … 'cause they said, you can bring someone but they won't pay, like they've got to pay for themselves to come over, 'cause you know how you get funding like to go on the flights from the hospital and stuff, eh, so, they said you'll have to come yourself unless you get someone to come*

with you, I was like a bit nervous about, if I did go by myself, I'd be really nervous.

Lisa: Why would you be nervous?

Kate: 'Cause I wouldn't know where I'm going and there'd be people everywhere and it'd be like "Who do I go to?" you know [laughs], so ... like, probably just, I don't know be afraid to ask anybody, like, "Where do I go?" and stuff … so I'd probably be more comfortable taking someone with me.

Her reasons for feeling more comfortable about taking someone with her were actually revealed later on in the interview:

> *... I would like my dad to come 'cause he seems to know everything about me so, it'd probably be, like, easier to explain to him with him there, 'cause he'd like fill in all the details, you know.*

It seems Kate has had a minimal level of involvement and ownership of her health care so far, so perhaps similar to the quote from HCP 08 previously, there is a sense that the extent to which her father has been addressed in the consultations has tempered her ability to renegotiate her role within this relationship within the context of her health care. Her father, Peter, however, expects that his role will be somewhat renegotiated as a result of Kate's impending first attendance at the adult hospital, but will require some letting go on the part of he and his wife:

Peter: You know we won't be there for her year in, well, we will be there for her but, you won't be there holding her hand like you have done for the last sixteen years, you know so, it's … it'll be a bit daunting.

Lisa: How does that make you feel, the, the thought that you might not be there to hold her hand through it now she'll be into adult care?

Peter: I think it's just going to be a learning, this, it's just going to be a learning curve, not only for, for Kate, but for us as well. You know the … we will just have to learn that you have to let go, you know and, and, you never do, you never do let go oh your child but em, you're going to have to say, "Right, she has

> *to deal wi this," and, "She has to get on wi this," it's … although we're so far away, you know that it'll be a case of, we're only at the end of a phone … so if she, if she needs help, she just picks up the phone and we're only forty minutes away in a plane so, you know that's there but em … hopefully she'll be able to deal with it, you know …*

Whilst issues surrounding the renegotiation of the relationship between Kate and her parents appear particularly prevalent from both their perspectives within the context of their transition experience, little evidence was available within the case notes, or within the narrative of the nominated health care professional interview, to suggest these issues were reflected clinically. In fact, in her case notes, the only evidence which provided some insight into Kate's relationship with her parents in the context of her health care was in relation to her attendances at her long-term follow-up appointments, in which she was always accompanied by one or both of her parents. The particular extract below is indicative of not only this, but also of the nature of the dyadic experience of transition, as it was reported that both Kate and her mother had a number of anxieties about moving to adult care the first time this was raised. The following extract also reveals the involvement of Kate's mother in her health care, despite Kate's earlier quote in which her dependency on her father was more explicit:

> *Kate is of an age when she should be transferred to the adult sector. Both she and her mother have some anxieties about this and so I have suggested that we see her once more next year then transfer her.* (Paediatric case notes, Case 10)

Integral to people's accounts were the relationships that had been formed and fostered between young people, parents and health care professionals during the young person's illness experience. Such relationships were central to people's transition experiences, particularly as the physical move to adult care instigated a change in the structure of these relationships in some way. For many young people and parents, the loss of these health care professional relationships offered a particularly poignant marker that the move from paediatric to adult cancer care resonates far deeper than that implied by focusing on the simplicity of moving from

one hospital to another. Such a finding is demonstrated in the following quote from Martin from Case 09, as he describes his experience of learning he would be leaving the paediatric hospital in concrete terms for the first time during his last appointment there. For Martin, seeking some kind of satisfactory closure with his relationship with his key health care professional, HCP 09, was important to him. However, such an opportunity was denied, which appeared to be particularly influenced by the lack of structured planning and preparation surrounding his move to adult care:

> *I mean, it's not really sank in yet, but it's sort of when you think that you know someone, or you know people and they, you then think that you're never really going to see them again, you just sort of think, aw naw, I had a good friend there and suddenly it just, you know, it takes you, it takes, it's quite annoying 'cause it takes you that long to know someone that well and then it's just, within seconds it's gone ... and it's annoying, it's a bit sadness really, 'cause you know you won't, you know, see them again. Em … and [sighs] … you just feel like something's missing as well, 'cause you don't really know what's going on anymore with their life because, like I was used to going in and people saying, "How are you?" "Oh, I'm fine, how are you?," but that won't happen because I can't speak to the same person, so I won't know how they are doing …* (Martin, young person, Case 09)

Martin found the haste that his relationship, indeed his friendship, with HCP 09 was brought to an end to be particularly unsettling. These feelings appear to be magnified by both the swiftness of the change in relationship status from his perspective and his lack of awareness that such an event would arise at this time. The lack of any structured planning and preparation for the move to adult care and its impact on his readiness from a relational perspective is stark in Martin's case. The management of his last appointment at the paediatric hospital only exacerbates the need for an appropriate environment and opportunity for young people and parents to acknowledge and renegotiate their relationship with such a key individual in a satisfactory manner. On Martin's last day at the paediatric hospital, due to the number of patients attending and late-running appointments, an additional paediatric

oncologist was assigned to the clinic. It transpired that Martin was seen by this individual, rather than HCP 09. However, as Martin's mother, Helen, indicated, *"this was actually the first appointment we've ever had at [paediatric hospital] where we didn't see [Name] … in the 12 years [laughs]."* Although Helen recounts with some humour their last paediatric attendance, the finality of her and Martin's last interaction with HCP 09 is striking:

> *That's what I mean, 'cause it was so sort of sudden, there was no sort of time to think about it, so you didn't have time to … like say, "Martin, is there anything you want to say to [Name]?" or you know, any of the staff, or any of the nurses or, you know, there was nothing. It was just a case of like we met him in the corridor, "Right bye," "Bye"… Oh, okay, and he just sort of said "How's it going Martin?" and, you know, "We'll see you again," sort of thing, and we're off. He says, "You're off to [adult hospital], I hear now," and we went, "Yeah," and he says, "Right, okay, that's great, bye,"… and he shot off to get his next patient [laughs] … right, okay, but that's doctors for you [laughs].* (Helen, mother, Case 09)

There is a real sense of finality in Helen's narrative, but it may be inferred that had the two been able to engage in some kind of structured planning and preparation, this finality would have been better assimilated. The finality appeared not be prioritized or recognised by the health care professional or the rest of team in the context of either her or Martin's transition experiences, a finding which was reinforced by the absence of any correspondence in Martin's case notes which indicated moving to the adult sector had actually been discussed with him prior to his last appointment at the paediatric hospital. Indeed, narrative from HCP 09 also suggests that at no point had a move to adult care, and certainly a move of such imminence, been discussed with Martin:

> *… I can't really recall having a proper discussion about it [transition to adult services] to be honest, so I'm wondering whether it may be on my, I think I saw him last in em … [refers to notes on computer] … oooh, in April 2010 … that's*

> *the last letter that I've … [slight pause] … there was issues about him driving … em … I haven't made a note that I've actually even discussed it with him, to be honest …* (HCP 09, Case 09)

Thus, it appears little opportunity had been provided for Martin to acknowledge the importance of his relationships with his health professional team, the changes within these engendered by his move to adult care and his readiness for such a move. In fact, it appeared that Martin had been provided with very little opportunity to engage in any discussions that would be considered par for the course within a transition planning and preparation context. The lack of opportunity to do so, particularly within the context of renegotiating his relationship with Martin, seem to be influenced by HCP 09's clinical perspectives on what defines the move to adult care, as, for him, the continuity of involvement of the paediatric oncology team in the new transition clinic at the adult hospital, albeit reduced and on a rotational basis, would ensure the maintenance of these relationships in some way.

> *It's just really seeing them in an adult environment in case they need to come in for some investigations where it's not possible for us to do them here [paediatric hospital] … so it should be seamless, really.* (HCP 09, Case 09)

However, as Martin's and Helen's narratives indicate, to ensure this seamlessness, the move to adult care should be considered within the context of a wider range of experiences, of which their relationships are just one element, to ensure people are ready for changes that are far more complex than simply a change in physical environment. Thus, there is a need to prepare people for changes to their relationship structures, particularly the relationships between patients, parents and health care professionals to make the process of transition as seamless as possible and to ensure each component of this process is addressed in the most appropriate manner. If there is no appropriate environment or forum in which appropriate planning and preparation for changes or endings with such relationships can be acknowledged, people may leave the paediatric environment feeling their relationships are in many ways unresolved. As such, these feelings may temper people's experiences in the

longer term, particularly in the context of accepting why particular relationships become renegotiated during the course of their health care experience. They may, like Jordan from Case 03, be left to make their own assumptions for the ending of significant patient/health care professional relationships if not acknowledged within the context of a defined transition planning and preparation process:

> *I mean, it was just, it was just a case of I think the reality was that, you know, [paediatric hospital] didn't really know where to send me em, and that was kind of it. Eh, and I don't know why I never got seen by the oncologist/ haematologist again in [paediatric hospital]. I, I … it was, it was just … I, I just saw them and that was it and there was no "This is us getting rid of you now Jordan … off you go, great," you know, "Professor [name] the endo-, endocrine will see you now," it was just, I just never got another appointment and another appointment was never made and that was it. I, I didn't feel upset, I was just a bit, I was more curious, I was like, "Ooh, right! Well, they mustn't be bothered with me now," and, and that was it, you know, em, cause I used to see a joint, there used to be a joint clinic, it was always the oncologists, you know, Dr [name] the oncologist there and eh, Professor [name] the endocrine guy sitting beside each other so they used to just sit and chat and then they used to chat about endocrine and used to, used to chat about general stuff and what not … so it was all, it was just really, really bizarre you know, just em, I just feel like … I, I, I just, I do wonder if it wasn't for me being a bit pushy and me being a doctor… I wonder if I, if things would have moved, I do wonder em, what would have happened … eh, would I still be going to [paediatric hospital], be still sitting in that paediatric room with the, the toys and small chairs?* (Jordan, young person, case 03)

It appears that Jordan's movement from paediatric to adult care, which would be considered a transfer rather than a transition as a result of a lack of any structure or process surrounding the physical move, was very much self-directed. As a result, he considers whether he would actually still be attending the paediatric hospital had he not requested his follow-up to be moved elsewhere. Although he told of not feeling

upset by the unsatisfactory ending to his relationship with his paediatric team, there is a sense that the way this relationship ended is still at the forefront of his overall experience. However, it seems that the reality of what the experience of ending a long-term relationship between the patient and health care professional is actually like was poignantly presented to his nominated health care professional, HCP 03, in the context of his own recent retirement. This, he acknowledged, was an emotional experience, but much more so than in the context of his previous experiences where he has ended relationships with previous young people he has cared for who move to adult services:

> *Yes, I mean I think it is strange actually, I mean, it was highlighted for me, I mean, as I mentioned to you I retired anyway last month, and I have to say, actually saying goodbye to families in that context, although in practical terms is no different to saying goodbye to somebody who's just moving on to adult services, em, I found much more emotional from a personal point of view than just, well, you know, you're at a stage now where it's appropriate for you to move on and somehow that seems okay, which is not to say that you know, obviously, when you've known people for you know maybe twenty years or more, sort of boy and, and man, as it were, that it isn't a, a sort of emotional wrench I think, and you know, I think that's probably one reason why some paediatricians do hang on to these young people longer than perhaps they should em, because you know, it's not in the paediatrician's nature to let go from that point of view when you've got to know families very well and you feel a sort of protective … towards them particularly as eh, you know, as I say, in some situations you feel, well, maybe there aren't appropriate adult services for these young people so you do feel, you know, protective and, and possessive in a sense about them and that's not always appropriate.* (HCP 03, Case 03)

HCP 03's quote is suggestive of a culture of paternalism within paediatric oncology care. Whilst this is by no means unique to this context, as this has been acknowledged as an issue within other health care contexts, it is important to acknowledge within the current context and the context of the current study and its findings. The level of

protection that HCP 03 discusses can be further understood within the context of section 7.4.2 that follows, as the findings there indicate that for some young people and parents, losing the familiarity, safety and security afforded by the paediatric hospital, which is often borne from the protection such a team can and do offer, can influence their experience of readiness in the context of transition. The protection so inherent within the paediatric oncology team may mean that even when the relationship has ended, a reciprocal level of protection endures. This was particularly evident within Jordan's mother's narrative:

Liz: Yeah, in a way, but, in a way, I know it sounds silly that you're sad to leave going to a clinic in a hospital, most people would say, "Hurray!," but when you've gone for so many years – it's different, it's totally different. You know, I mean, there's a lot of other places you just want out of but I didn't feel like that there.

Lisa: Why is it so different?

Liz: I think because it was such a serious illness. You know I, I think that's why it's so different, I think it's because it was, it was a very, very, very serious illness and I think you kind of feel you owe them a lot, you know what I mean? You know, I think you do, owe them …

Lisa: Tell me a little bit more about that, you owe them, what do you owe them?

Liz: Well … [laughs] … well I mean let's face it … y, y, you owe them that Jordan's still here, you know because he was very ill. I mean, Jordan was very, when Jordan was diagnosed em, with [diagnosis] he was really, really ill, you know, I mean he, he was, as Dr … [name] said, the next stage would have been Jordan would have had a stroke, he was that ill, so I think perhaps you, you realise, it's maybe wi' hindsight you realise how ill he was, maybe at the time you don't you know, because I don't think you want to accept it …

7.4.2 Loss of the familiar

The sub-theme, 'Loss of the familiar', depicts those losses that featured prominently within the context of people's transition experiences, with the term adopted in recognition of the various losses that arose. Such losses included the loss of safety and security afforded by the paediatric hospital and staff and the loss of control for parents in terms of their son or daughters health care. Although losses such as these were acknowledged by health care professionals, the individuality of their impact on people's transition experiences were rarely considered or incorporated into any transition planning and preparation. Indeed, readiness for losses and changes such as these were not formalized or assessed in any way, meaning the complexity of these and the impact on people's readiness in the context of their transition experience was often not considered, as indicated by the following quote from Sarah in Case 06:

> *I just found it really emotional because I feel like most of my life has really been in [paediatric hospital] and like everything that's happened to me is thanks to them and I just feel, I felt kind of guilty in a way that I was leaving …* (Sarah, young person, Case 06)

The familiarity of the paediatric hospital and team and their influence on her readiness to leave such an environment is evident in this extract from Sarah, as she talks of feeling guilty about leaving this physical location and its staff. Though her case notes provided an account of some of her concerns about going to adult care for the first time, feelings of guilt about leaving the paediatric hospital were not reflected in these. Rather, the fear and trepidation Sarah felt about attending the adult hospital for the first time was evident, as revealed later in section 7.4.3. However, it seemed that in an attempt to quell such anxieties, Sarah's physical move to adult care would only occur when she felt better able to do so:

> *In terms of follow-up for [diagnosis], we will not rush to send her to [adult hospital] and wait until she is comfortable.* (Paediatric case notes, Case 06)

It is possible to discern from Sarah's case notes that she felt particularly anxious about the prospect of leaving the paediatric hospital, yet, as previous narrative from Sarah in section 7.3.1 revealed, her departure from the paediatric hospital came as somewhat of a shock to her and was a particularly emotional experience. Nevertheless, it is not clear how the paediatric hospital would have ensured that Sarah did feel comfortable for the move, but it is clear, from what Sarah says in her interview, that in many respects she felt neither comfortable nor ready for the move. It can therefore be inferred in this instance that there was little harmony between patient experience and clinical practice.

However, it was not only Sarah who was reticent to leave the paediatric hospital, as this was also similarly echoed by her mother, Susan. Indeed, Susan's readiness, too, was influenced by her concerns about leaving the paediatric hospital behind, but it seemed the reality of the imminent removal of the familiarity associated to the paediatric hospital was at the root of her trepidation:

> *I think it was just the, the, I suppose it's the security blanket of being at [paediatric hospital], that's where we've been for, you know for the last 8 years. Em, and of course we know all the doctors and nurses and I suppose it's just that of going … you're stepping out your box into something … an unknown territory, and I suppose it's kind of that and, and … yeah it's just a bit scary, really …* (Susan, mother, Case 06)

Leaving the safety and security of the paediatric hospital in the move towards this unknown territory was an issue that resonated with many young people and parents in the study. Some had experiences akin to Sarah and Susan, in that a feeling of trepidation underlined the loss, whereas for others, they were ready for such a loss within the context of their wider transition experiences. It was, however, almost always considered by health care professionals that all young people were ready to leave the familiarity of the paediatric hospital, with parents struggling more so with this, as reflected in the quote from HCP 06 below when discussing Sarah and Susan's experiences:

> *E-m … yeah, I would think they were ready, you know, they might not have, they, you know, mum might not have thought she was, but yeah, I think they probably were, yeah. I think, you know, and they, probably none of them ever think that they're ready to leave and can manage with, without us even though the contact is becoming less and less and less, but em … no, they all, they all manage at the end of the day. Yeah. And they, you know, and if they, if there's a problem they'll always be on the phone and sort of say, "Oooh … can I just ask you about … ?" [laughs] … 'cause that's still there [laughs] … Yeah, so they're not totally abandoned.* (HCP 06, Case 06)

As illustrated, in the interviews, several of the participants talked about changes and losses they were experiencing in the context of their transition. It became apparent upon analysis of the data that such losses contributed to people's experience of readiness in this context, particularly as many of the losses were imposed by the actual movement from paediatric to adult cancer care.

Indeed, the most significant change for young people and parents in this study was that of the hospital environment in which the young person would continue to receive their long-term follow-up care. Although changes in the visual structure of the environment and its associated surroundings and organisation did temper people's expectations of adult care, as revealed in section 7.4.3 that follows, it was more what the paediatric hospital represented to young people and parents on a personal level that induced feelings of loss in several of the participants. For many young people and parents, the paediatric hospital and its staff afforded a particular level of safety and security; a result of the trust established between families and their health care professional team. Indeed, such trust was a defining feature of the childhood cancer experience for all participants in this study, with this trust augmented throughout the entirety of their experience, as the significance of the longevity of the childhood cancer experience in section 7.3.1 illustrated. The importance of trust between patients and doctors has been acknowledged previously, both in the context of people's experiences of childhood cancer (Harrington *et al.*, 2009) and those diagnosed in adolescence and young adulthood (Grinyer, 2009), with the formation of

such relationships often deemed to be “out of necessity of survival”, rather than by traditional means such as by birth or through choice (Harrington *et al.*, 2009). Thus, the very prospect of losing the safety, security and trust embedded within these triadic patient/parent/health care professional relationships for some participants in this study penetrated much of their narrative, with their readiness for such a change threatened by the individuality of their experiences. This point is suitably exemplified in Case 12, as the following quotes from Natalie and her mother, Sheila, convey the impact the prospect of losing the familiarity that surrounds their experiences at the paediatric environment has on their readiness in the context of their transition experience:

> *Lisa: How, how did you feel going there last week and finding out that it would be your last time?*
>
> *Natalie: Well I … it's no as bad, but I wanted, I wanted to really stay there 'cause I've been there for so long and I ken everybody and … just, I trust everybody there and going somewhere different I'm no going tae ken anybody … And they, they dinnae, well they, they dinnae ken me, they're gonnae obviously wi the, my medical and stuff and everything, my notes and that, but they dinnae ken me like everybody there [paediatric hospital] does [pause] …*
>
> *Lisa: And how, how do they know you, apart from your medical notes, do you mean?*
>
> *Natalie: I mean like, they don’t, they dinnae ken me in person. Like they, they … at [paediatric hospital] they know me, who, but they're only gonnae ken me fae ma notes and like they're no gonnae ken what, like … you ken what I mean?*
>
> *Lisa: Mm-hmm. And how does that make you feel then if you think that they won't know you as a, a person?*
>
> *Natalie: I don't know, it just … I don’t, I dinnae even ken, I just feels it's going to be different, I dinnae ken why, but it's just going to feel different. I’ll get used to it.*

Lisa: *Mm-hmm, what's it like for you to think that at [paediatric hospital] they do know you as a person?*

Natalie: *I don't, I … just trust them and they're my friends and … I've got quite em good relationships wi some oh them there. I'm just going to, well actually I'm no going to leave them aw because some oh them, I'll be working with over there. I don't know it just feels different.*

From Natalie's quote here, we sense the importance she regards being known by her health care team as a person, borne from many years of attending the hospital and establishing a relationship with them in the context of her health care, and not just from her medical records. This familiarity, of the staff with her and vice versa, contributed to her later descriptions of being happy when she was at the paediatric hospital. However, it is clear she has some anxieties about how she will be treated at the adult hospital, despite some awareness that she will continue to receive care from some of the same staff members from the paediatric hospital at the adult hospital. However, it appears Natalie would have benefited from some further planning and preparation for her move to adult care, as we sense her hesitance to remove herself from the familiarity of this approach to her care. It is also apparent within her mother's dialogue that she, too, shares these concerns about extracting herself from the familiarity of the paediatric hospital and environment:

Lisa: *Just thinking about, you know, thinking about not seeing the doctors, leaving the doctors there, you said that's hard even for you … tell me more about that.*

Sheila: *Well it is, 'cause I think it's, it's just a security thing again I suppose and a trust thing … em, I know the amount oh times Natalie's had to go in and have surgery on her head, I know what the surgeon's done and how capable she is oh doing things, and just thinking that, I suppose it's aw aboot going to somebody that dis-, you, you dinnae know and they dinnae know you and, even though aw your information's in medical records, it's good 'cause Natalie's got quite a good relationship wi' them as well and they've been, they've done so many things for her …*

Lisa: *Mm-hmm.*

Sheila: *… that they know her, like inside out, eh, and that concerned me a wee bit 'cause you worry thinking, well, these people are so good at their job, you know them so well and you trust them so well and it's really hard to move away and start dealing wi' other doctors that you dinnae ken what they're going to be like and … you dinnae ken how tae speak to them and …so aye, it is hard to move on.* (Sheila, Mother, Case 12)

Evident within both Natalie and Sheila's quotes is a sense of the inherent trust they place in the staff at the paediatric hospital and the security this affords them both. The use of terms such as 'trust' and 'faith' emphasize the significance of the hospital and staff to them, but there is also a sense of dependency on Sheila's part on both the hospital and the doctors, with some discernible reticence on her part to move on from these. An awareness of this dependency was revealed in the interview with the nominated health care professional, HCP 12, as he considered this to be a complicating factor in Natalie and Sheila's move from paediatric to adult cancer care:

HCP 12: *… I think it'll be, I think it'll be very difficult for her and her mother to move on from [paediatric hospital] … mm-hmm …*

Lisa: *Why is that?*

HCP 12: *Because it's been like a second home to them for so long really, so it'll be very hard for them. They're unlikely to find the same kind of service you know, it just doesn't happen in the adult sector … you know, you can't just ring up and [pause] … so I'm sure there must have been occasions over the last, you know, 10 years or so when … she's [Sheila] virtually just turned up with her [Natalie] 'cause she was anxious about something, you know … 'cause we're always available to see them if they need to be seen … and obviously try and sort out their problem, whatever it is, so I think that they, you know the problem is it might be quite difficult, so we're hoping that it's going to be alright but you know we'll have to see. It'll be a challenge to transition Natalie.*

Despite the perceptible anxieties surrounding Natalie's move from paediatric to adult cancer care in the triad of interviews and the impact this is likely to have had on her readiness in the context of her transition, such anxieties were not reflected at all within Natalie's case notes. Some correspondence indicated a referral for Natalie to transfer to adult psychological services had been made approximately three years prior to her leaving paediatric care, but little detail was recorded about her move to adult care for continued long-term follow-up. Particularly so, scant regard was paid to the issues of trust, security and dependency on the paediatric hospital and staff so raised by Natalie, Sheila and HCP 12 and which may be considered to have had a significant impact on Natalie and Sheila's readiness for the move. The only evidence available to indicate a move to adult care had been mooted was in a piece of correspondence to Natalie's General Practitioner, in which transition to the adult hospital for her Endocrinology/Oncology long-term follow-up was raised briefly:

> *We will plan to see her again for review at this clinic [endocrinology] in six months' time and then plan transition to the joint [endocrinology/oncology] clinic at [adult hospital] in approximately [date]. Natalie is aware of these plans.* (Paediatric Case Notes, Case 12)

As with Natalie and Sheila, familiarity with the paediatric hospital and staff also embodied a level of safety and security for other young people and parents, such as Kate and Peter from Case 10. For Kate, like Natalie, the reality of no longer being part of this safe and secure environment was of concern, particularly as much of what was familiar to her and helped define her experiences at the paediatric hospital was threatened by her move to adult care. Her relationships with staff, the location and layout of the hospital, her role within her long-term follow-up appointments and her ownership of her health care experience are to be re-established in the adult hospital, all prominent concerns within this context for Kate. Indeed, her heightened anxiety surrounding these issues is discernible in the following series of quotes:

> *It is emotional because you, I've been going there for fifteen years and like, I've … and I've known the place so well and it's like all the nurses and stuff and then,*

you get moved [laughs], like suddenly 'cause it's passed so quickly like that and you get moved to like a new environment, you're, you're kinda lost, like … "Oh, where am I going? What am I doing?" like, "Who are you?" you know, and stuff like that, so it's quite … I suppose it's kinda difficult moving to a new hospital, you know ... (Kate, young person, Case 10)

And later in the interview:

Kate: They've [parents] always come with me like. Like every time I go into like see a doctor, my mum or dad would come in with me and they would like answer all the questions for me really and I'm like … and then they would ask me a couple of questions just like, "Are you well?," "Are you healthy?," "You're not doing this, you're not doing that," and I'd be like, "Yes. No. Yes," and they'd be like, "OK, that's fine then," and then they would just ask like my parents, like … "Has she had a normal diet?," "Her blood test is fine," like, stuff like that.

Lisa: Mm-hmm.

Kate: Yeah. So they've always, like, came in with me to like, answer the most, the more technical questions.

Lisa: And do you feel you know enough now that you've left [paediatric hospital] to kind of start to manage that on your own a bit more in adult care?

Kate: Yeah … I think so, like, I'll probably, like, need to learn a wee bit more, like, if they ask me a question and I don't really know the answer I'll probably have to ask, like, "What do you mean?," and then they'll probably, have to explain it to me, and I'm like … "Oh, OK," … and like, answer the question. So, I'll probably have to learn a wee bit more, like what to say to them, like, if I don't know the answer.

Despite these concerns, Kate talked elsewhere in her interview about believing the move to adult care was a "step up", an accepted part of her growing up. It may be inferred therefore, that she felt ready for this event in the context of other transitions

and events in her life, with the passage of time since such a move was first mooted and her recent last attendance at the paediatric hospital, critical to the development of this readiness. This passage of time is reflected in her case notes, as evidence suggests that such a move had been raised with her previously when she reached an age when the first introduction to this event was deemed appropriate. However, it seems that age was not a sufficient marker of readiness in this instance, as Kate was somewhat lacking in a similar resolution to that which she holds now compared to then, as at that time, a move seemed to be particularly anxiety-provoking for both Kate and her mother. However, no evidence to suggest the roots of this anxiety and ways in which she could be supported to feel better ready for the move, save delaying the move by a year, were captured or reflected in her case notes. Only the quote illustrated previously in section 7.4.1, and as repeated here demonstrates this:

> *Kate is of an age when she should be transferred to the adult sector. Both she and her mother have some anxieties about this and so I have suggested that we see her once more next year then transfer her.* (Paediatric case notes, Case 10)

Now that she has actually left the paediatric hospital, Peter, Kate's father, is aware that the move to adult care means they will lose much of what is familiar to them within the boundaries of that paediatric environment. Like Kate, Peter is aware within the context of the move to adult care that not only will Kate be forced to re-establish herself in many ways in this new environment, but so, too, will he and his wife. The reality that they will be relegated from the familiar role they hold within her health care ignites a loss of control in many senses from his perspective:

> *Peter: … but, as I say, Kate's now going to move on and just get dealt with through an adult basis and hopefully, as I say, we, we'll never ever strike up the friendships wi [adult hospital] staff that we had with eh [paediatric hospital] staff, because we won't be involved. You've kinda, your involvement's finished in the sense of a medical sense. They won't, they won't want to know us because eh, Kate's an adult so aw they want to do is know Kate … they'll*

want to learn about Kate and know more about Kate and … we'll be just getting taken out the equation altogether, you know …

Lisa: And how does that feel for you?

Peter: It's one oh these … there's, you've not got any control over it and at the end of the day em, it's the way it is, it's life you know em we've done our part, you know we've been there through all the hard bit, I suppose you feel like you, these doctors and nurses that are going to deal with her now, although they know what she's came through, you think, "You haven't held that child down by the shoulders and let somebody stick a needle into her spine," you know, em, you've not done that, you've not, you're no stood there and cried tears over her and, like, when she's screaming, shouting, "Dad," you know to get folk to stop hurting her … you know and sweating buckets oh blood, it's horr-, it's horrific, you know, but they know, well they all know exactly what she's came through, you know, and it's probably a good thing, the fact that we're not involved anymore … you know, em 'cause eh, you wouldn't want to be, you wouldn't want to embarrass an adult, you know, as all parents do.

It seems that Peter has resigned himself to losing the familiarity of their role within Kate's health care within the context of her growing up and the inevitability of the redrawing the boundaries in their relationship in this context. Such findings can be further explained with reference to section 7.5 of this chapter, which details the theme 'A process of change'. That theme illustrates how people's experiences of readiness in the context of transition were frequently contextualized by other components of their experiences, particularly so the simultaneous life transitions that occur for young people and parents alongside their movement from paediatric to adult cancer care.

The findings above have highlighted the loss of familiarity that is significant within people's experiences of the process of transition, particularly so in the context of the loss of the safety, security and trust afforded by both the paediatric hospital environment and the paediatric health care professional team and as introduced latterly through the exemplar quote from Peter, a loss of control from the parents perspective. The loss of the familiar in this context meant the move to adult care was

the catalyst for a number of losses not only from a young person's perspective, but so, too, for their parents. Furthermore, the findings illustrate how the planning and preparation that had helped to inform their transition frequently influenced people's experiences of these losses and their experience of readiness in this context. It can therefore be cautiously inferred that providing little opportunity for any structured transition planning and preparation means young people and parents will struggle to assimilate the reality of moving on from paediatric care, as their readiness for this change may be threatened by their reticence to lose what is familiar to them.

The extent and variability of the loss of the familiar people experienced is indicative of the complexities surrounding transition. For some young people, the significance of the move to adult care was such that the experience was in many ways defined by an assault on their sense of self. For Sarah from Case 06, this was certainly the case, as her departure from paediatric care meant she struggled to assimilate her withdrawal from a structure in which she has been very much defined by her childhood cancer. Having cancer as a child appears to have defined Sarah's life and identity in many ways, as she discussed during her interview how her experience has changed her as a person and has informed and shaped her career plans, with an intention to study paediatric nursing at university and ultimate desire to work in paediatric oncology. However, for her, her improved health, coupled with her departure from paediatric care, means this identity is threatened in many ways. Her reticence to let her childhood cancer go may impact on her readiness for her move to adult care, as she implies she will be in some way forced to lose this part of her identity:

> *… the fact that I am better is quite upsetting because, I don't know how to explain it without sounding like a … like, sound really stupid, but, basically I, I seem to cling onto the fact that I had diagnosis and see the fact that I'm going to be moving on … I don't really want to let it go and if I'm going myself then, you know, I probably will just let it go, but because it's been a big part of me I do try and hang on to it because before I was ill I was a totally different person than I am now.* (Sarah, young person, Case 06)

Again, the complexities associated to the transition experience are revealed here. Sarah's quote demonstrates again not only the permanency of the childhood cancer experience, but also the individuality of people's experiences and the need for appropriate planning and preparation to ensure people have the opportunity to gain some resolution on their experiences thus far. Sarah's case notes were, in fact, lacking any detail about the root of her concerns surrounding her move to adult care, although they did capture how she was particularly anxious about the prospect of attending an adult hospital. But, as the following quote from HCP 06 reveals, moving to adult care is often seen as opportunity for many young people to move on with their lives, but, as we saw from Sarah, losing part of herself in this way is not something she appears ready to do.

Lisa: *Yeah, and did you get a, a sense for what Sarah and her mum felt about leaving here?*

HCP06: *E-m [laughs] … Sarah's mum really quite liked coming here and eh, you know they, it, it's just because they've been coming for such a long time, and eh, you know with Sarah … I, latterly would only see her like if she came up here after clinic, 'cause I didn't always, I don't always do the em, the Late Effects Clinic, em, but you know, it's … I think for the pare-, … the kids are probably better able to leave than the parents are because the parents know us, we know them, quite a lot of them have, you know, quite good relationships with various members of the staff and everything, em, they know they can phone up and ask us about, you know if, you know you could be umpteen years out from treatment and the way [paediatric oncology ward] works, you can still phone us and sort of say, "Oh, I'm having a blind panic about whatever," and somebody will talk to you and say, "Look – it's fine, don't worry about it," or, "OK, just bring them up," so I think maybe the parents are more cocooned by us than the, than the children. I think the children are often perfectly well able to move on eh, in many ways a lot better than their parents, and if you see, if you see the kids in a Late Effect, you know in, in an out-patient clinic post-treatment setting, em, I'm not particularly talking about Sarah but em, like I, em, do the Oncology Clinic … you know, there's a lot, a lot of the kids have been very small*

> *when they've been diagnosed and I frequently say to them, you know, "Do you remember anything about your treatment? Do you remember when you used to come to the Day Care Unit or [?]," no there's no, you know, there's never any terrible huge scar that everybody thinks will, you know, have been ingrained into this poor child's eh, subconscious kind of idea. They're all well, they're fine, they've got over it em … some of them you, you say to them, "Do you, do you actually know what was ever wrong with you?" and you'll get the odd one that doesn't, has got no idea, that the parents have never, never said.*

Although HCP 06 only fleetingly refers to Sarah in the above quote in the context of her not being one of the young people who have no awareness of their illness history, there is a sense that the individuality of people's transition experiences can be negated. As Sarah's previous quote demonstrated, there are occasions when the experience of childhood cancer can be "ingrained" into not only people's subconscious, but so to their sense of self. In Sarah's case, this can be further understood from considering the most profound long-term late effect of her treatment; her steroid-induced pancreatitis. As the following quote demonstrates, her mother Susan is also acutely aware of the individuality of Sarah's illness history and experiences and the impact these have had on her. From Susan's perspective, there is a sense that Sarah feels different to her peers, but as her parent she has tried to contextualize the challenges she faces now by comparing her experience to others, particularly her experiences during treatment. Yet, there is still a sense in Susan's narrative below that Sarah struggles with the implications of her treatment and the impact this has on her life now as a teenager and in her future life:

> *That was really the only big issue I've got really, about is, is the fact of the pancreas and that she does struggle and says, "Why m- ?" … you know, "Why me?" and, you know, and, "I'm on Facebook and girls that were in hospital with me they're out partying and dancing and having a drink," and you know, but I said everybody's, you know … and as the Consultant said most people are left with something and Sarah was, lucky's not the right word, but through her chemotherapy she wasn't really, touch wood … she was always quite well and*

she wasn't ill, as such, but a lot of the other children were, you know they, they were more, their lives were more debilitated, like they were in wheelchairs or couldn't walk properly or they had other complications through the, out their treatment where Sarah didn't really have any comp-, apart from her pancreas em, so I was trying to explain to Sarah that you know although you've been left with this, and you see other children who are not left with anything, they had complications throughout their treatment, you know, so it's, they all get something but trying to explain that a seventeen-and-a-half-year-old was a bit tricky. (Susan, mother, Case 06)

7.4.3 Expectations of adult care

The third sub-theme of the main theme 'planning and preparation: transition or transfer?' is that of 'expectations of adult care'. This theme also highlights the importance and centrality of planning and preparation in terms of ensuring people's readiness in the context of transition and was drawn from prompts in interviews such as 'what do you know/what did you know about [adult hospital] before going there?' and 'what do you expect/did you expect [adult hospital] to be like?' It emerged that young people's expectations of adult care were variable and covered a spectrum of feelings including fear, anxiety and excitement. Despite such fear and anxiety, many still expected the move to adult care to be positive, particularly so as it would mean they would both be treated like an adult and be around age-appropriate peers. These were experiences many young people appeared ready for, as reflected in the following quote from Jennifer from Case 08:

… I thought, I expected, you know, like you, you get in your head, hospitals are like the big sort of scary places and stuff like that, like I mean, I should know what, me personally, I know that they're not because obviously I've been around a couple of hospitals and aw that but for some reason I was still thinking it was going to be, oh really awkward 'cause everyone there's going to be like really young and I didn't know how the people would be 'cause obviously I know that the, the nurses at [paediatric hospital] are having to be friendly and sort of

> *"Ooh!!," 'cause they're wi kids and, you know obviously they're, it wouldn't be as, as sort of childish and happy as eh [paediatric hospital], but nah, it was a really good atmosphere, like, I mean, everyone's still talking and in a way it sort of felt more comfortable than at [paediatric hospital] because obviously in [paediatric hospital] it's just kids running around all over the place and you feel awkward being the oldest one there [laughs] … they're aw like three and you're sitting there seventeen … so like, nah I think, em, I dunno, it just sort of felt like I fitted in there [adult hospital] better.* (Jennifer, young person, Case 08)

Whilst not all parents had been to the adult hospital to where their son or daughter was moved, they did have some expectations of what this may be like, influenced by their pre-existing knowledge of adult services, some oncology related, others not. However, like Anne below, despite a positive perception of this first experience there, there was still the temptation to draw comparisons between the paediatric and adult hospitals:

> *… I was quite impressed wi the, I think it is quite a new set-up isn't it … there at eh, [adult hospital]. Eh, but aye, everything seemed slick enough and eh … aye, the only bit wis like when she got her bloods taken there last week, I don't think the woman could get her, could get it in sort oh thing and she's sitting wi a big black bruise on … her arm now, sort oh thing … "Oh, look at that, you wouldn't get that in [paediatric hospital]," she's saying [laughs]. So I don't know if it was just the woman was new or whatever, eh, but even she notices things like that, you know … but we had good rapport wi them all over in eh [paediatric hospital] in the haematology clinic as well, you know when you go for your thumb pricks, you know 'cause they get to know them as well as up on the ward … all the ones that are weighing and eh measuring her and everything like that you know, known them for years and years, it's obviously the same crowd.* (Anne, mother, Case 08)

Although Jennifer and Anne found their first experience at the adult hospital to be a positive one, many other young people and parents spoke of not knowing what to

expect exactly from the adult oncology services to which they were being transferred. Such inconsistencies in planning and preparation in this context influenced people's readiness for their move to adult care and, at times, it seemed that their experience was more transferable rather than transitional in nature. Mixed or uncertain expectations of adult care were not exclusive to young people and parents though, as many of the health care professionals interviewed, the majority of whom were from the paediatric sector, too, had particular expectations of adult care. Such expectations tended to focus on the differences in ethos between paediatric and adult settings, as reflected in the quote from Jennifer's nominated health care professional below. Often the comparisons drawn between the two environments were not entirely complimentary, yet these individuals often had a responsibility to prepare young people and their parents to move to adult care:

> *I think the adults do use the cloak of confidentiality to em, to exclude others, members of the family, even if the person does not have a confidentiality issue with the parent or carer being there but em it, it makes it a much easier consultation for the, the doctor involved if you're just dealing with a patient.* (HCP 08, Case 08)

It was apparent that participants, particularly young people and parents, had distinct perceptions and expectations of adult care prior to their actual attendance there, as illustrated in the previous series of quotes from Case 08. It seemed that people's constructions of adult care were largely influenced by the level of planning and preparation surrounding their physical move from paediatric to adult care. However, as discussed throughout section 7.4, processes surrounding the planning and preparation for such a move were variable and inconsistent for participants in this study. Such variability, it may be inferred, directly influenced people's experiences of readiness in the context of their transition experience, as many of those young people and parents who had a greater awareness of their move to adult care expected this to be positive and an opportunity for which they were ready.

This point is best exemplified by Daniel from Case 07, as his physical move to the adult hospital was preceded by some structured planning and preparation whilst at the paediatric hospital, during which his readiness for the move was, in many ways, assured. Although Daniel felt shocked and scared initially when he was first told he would be moving to a different hospital, the gradual introduction to the concept over his last couple of appointments at the paediatric hospital, coupled with the input of a Teenage and Young Adult Clinical Nurse Specialist, dissipated this fear.

> *Daniel: … I felt well, a bit of shock, no shocked but, a bit scared in the beginning that I was going to a new hospital and I just felt like, better because it was like an older hospital for teenagers, once they'd let [Name] tell me more about it.*
>
> *Lisa: Mm-hmm. But you were scared initially when you heard?*
>
> *Daniel: Yeah.*
>
> *Lisa: Tell me about that, what made you scared?*
>
> *Daniel: I don't know, just it'd be a new environment and I'd been to [paediatric hospital], I had, like I'd been going to [paediatric hospital] for like six year and it was just, like, a change, so it was like, kind of scared at the unknown kind of thing … and it, but it was fine once [Name] explained everything and I like went there, and it was like, I wisnae scared anymore.*

In addition to these prior meetings at the paediatric hospital, Daniel was actually invited to attend the adult hospital, specifically to the specialist teenage unit, prior to this first official appointment there and the CNS had an active role to play in Daniel's transition from High School to University. It appeared that Daniel was the only individual in this study for whom a structured opportunity to attend the adult hospital in an informal capacity prior to his first appointment was provided and accepted. For Daniel, such an opportunity was particularly important as he was worried initially about the different layout of the new hospital, so he needed to be able to walk about in the hospital prior to his appointment to gain some familiarity with the new surroundings. Despite having some initial nerves on the day of his first appointment, such planning and preparation positively contributed to Daniel's first experience there,

as he talked about feeling "well ready" to move on from the paediatric hospital, particularly as he felt much older than a lot of the other children at the paediatric hospital. However, what Daniel did not expect was the somewhat different approach of the first consultation in adult care compared to that which he had experienced previously at the paediatric hospital. Daniel told of being asked at his first adult appointment if he had ever taken any drugs or if he drank alcohol, at which he was shocked and "taken aback kind of thing" as he had never been asked questions like this before. Certainly from the transition of care summary document in Daniel's case notes it would appear that the likelihood of information of this nature being discussed as he got older had not been considered previously. Indeed, the only distinguishable information regarding discussions of a developmental nature in the context of his transition in that particular document was available in the life goals section, in which Daniel's achieved examination results and his desired further education and career goals were noted:

> *Em, well, I'd never been asked and like at aw off anybody like that ken, so I was like, I wisnae expecting it or anything … and then em, like I dinnae, like, I know that I don't take drugs so I was wondering why they were kinda asking, em, but it turns oot they were just asking in case I did wi ma medicine and that.* (Daniel, young person, Case 07)

Despite being confronted with the reality of the two hospital environments in this way, Daniel's readiness to move on from paediatric to adult cancer care was evident in much of his narrative and was echoed by his nominated health care professional during her interview. She, too, felt that appropriate planning and preparation was important for Daniel and this had fostered both his positive expectations of adult care and his readiness for the experience generally:

> *If I remember correctly, Daniel was quite … quite happy to move into adult services, em, I don't know whether that was because he felt he was of the right age or whether he felt just the timing was right, he was getting to leave school or whether he felt comfortable or more comfortable knowing that there was a*

> *degree of familiarity … I, I don't know why he felt more comfortable, but he didn't really have a problem with, em, moving into the adult side of things.* (HCP 07, Case 07)

The benefits of the structured planning and preparation with Daniel and his family was also evident within his mother's narrative, as she too appeared to have positive expectations of adult care in terms of its physical structure and environment. Although Morag talked of feeling nervous in the days leading up to and the morning of the first appointment at the adult hospital due to the initial unfamiliarity of adult care, knowing her son would be attending a clinic with people of a similar age to him appeared to quell her anxieties in some way. There is a sense that such a set-up was reassuring for her, which contributed to her own readiness for the move to adult care:

> *Well, I knew it had all been, all done up again and things like that, the only time I was ever in like [adult hospital] was actually [neighbouring adult hospital] where Daniel got his radiotherapy done and it was a kinda old building, it was full oh older people and, but I knew because they had said it would only be a certain age group that it would be more like his own age and things like that, you know. I think if they were to come from a kids' hospital straight into like being with older people and aw that I think that would have been worse … this way he's with sort of kids his own age and whatever.* (Morag, mother, Case 07)

Appropriate planning and preparation and the ways in which these can help foster the construction of positive expectations of adult care is of note and has bearing to the findings of this study, particularly as people's experiences of readiness were, in many ways, defined by the planning and preparation they had been able to engage in. As we saw earlier in section 7.3.1, Gary, from Case 01, positively viewed the opportunity to move on to a new surrounding and new ethos of care, particularly as this was an opportunity for him, and indeed his mother, to gain some closure on elements of their experience of childhood cancer. Like Daniel and Morag, Gary and Margaret also had a stepwise introduction to staff from adult care whilst still attending the paediatric

hospital, thus he very much perceived his move to be positive and something he felt ready for.

However, in contrast to Daniel and Gary, some young people's and parents' expectations of adult care were more negatively weighted. Of note, expectations of this nature appeared to be more prominent in those young people and parents who received minimal information about the adult hospital prior to leaving paediatric care and who had a distinct lack of planning and preparation for their move. Such a paucity of information only tempered much of the anxiety surrounding this move for some participants. Inherent in Sarah from Case 06's narrative, for example, is a sense that adult care will be very different from paediatric care, not only in terms of its visual aesthetics, but also in terms of the style of care and approach of the nursing staff:

> *I can imagine it not being very pretty. I can imagine it being quite, you know, blank and plain and old and scary and, I can't imagine them, you know when they're taking your blood being all like, obviously I don't have "magic" cream anymore, but, "Do you want magic cream?" or, you know, "Sit down here and … we'll be nice … 1,2,3 … you'll feel a wee scratch," I can just imagine them just being like, "Right … arm … blood," I can't … obviously that's probably really, there's really a lot of discrimination there but I just, you know, obviously you know, compared to [paediatric hospital] you do have a bad image of this big adult hospital, which probably will be lovely and everyone will be lovely …* (Sarah, young person, Case 06)

As we have seen elsewhere throughout this chapter, Sarah had been grappling with many aspects of moving to adult care for some time. Such was the extent of her anxiety associated to this experience that she elected to delay for presentation to hospital during an acute episode of her steroid-induced pancreatitis, as she feared she would have to attend the adult hospital. Her fear of the adult hospital appears in some senses to have manifested as a result of the experientially informed construction of adult care she has developed. It seems some of Sarah's friends have already made the physical move to adult care and their experiences have also contributed to the

dubiety that surrounds the move from Sarah's perspective, as captured in the following extract of a letter from her GP to her clinical team at the paediatric hospital:

> *I [GP] was concerned at her reluctance for a hospital admission more for the future than for this particular episode. Sarah explained to me that one or two of the children she met whilst she was undergoing treatment and with whom she still keeps in touch have required admission to [adult hospital] and have painted her a very grim picture of this.* (Paediatric case notes, Case 06)

Thus, it is possible to discern from Sarah's case notes that she did feel particularly anxious about the prospect of leaving the paediatric hospital, especially so in regards to potential hospitalisations as a result of any further bouts associated to her chronic pancreatitis. However, it seems a delay in presentation for one such episode was the catalyst for such anxiety to be identified. So, not only did the lack of planning and preparation in Sarah's case mean she had little opportunity to engage in any discussions which may have helped to quell some of her anxieties in this regard, it also meant her health was compromised as a result of her delayed presentation, such was the extent of her negative constructions and expectations of adult care.

Yet, it seemed that Sarah's perceptions and expectations of adult care were not entirely isolated, as there were some similarities with the expectations of her mother, Susan. However, Susan's disrupted narrative suggests that she is having some difficulties consolidating these expectations, particularly as she, too, focuses on drawing comparisons with the paediatric hospital, with her own constructions of adult care implying a fear that both she and Sarah will be abandoned in some senses by the adult hospital due to the lack of time staff may have available to spend with them. Thus, Susan appears somewhat reluctant to actually confront the reality of adult care, the differences between the two environments and the implications on their future hospital experiences:

> *I don't know, I really don't know. Em … I don't think it will … I, probably, I mean my, I … what I … I, I think they're so care- [ing], that's terrible, 'cause all nurses*

> *are caring and care about you but, they spend so much time with you at [paediatric hospital] and I don't know whether they'll have the same amount of time to spend with us and … I don't know, I don't … I really don't know, I'm … I mean, I don't know. I, I, I just … I don't know. I, I really can't, can't think about it, I can't think, I don't know. I … [laughs] … it's just, em … strange ….* (Susan, mother, Case 06)

Susan intimates in the quote above that she anticipates adult care to differ somewhat from paediatric care, particularly in terms of the way both she and Sarah will be treated and the likelihood of staff dedicating time to them in the way they are accustomed to in paediatric care. These expectations appeared to be shared by HCP 06, as she, too, believes care provision in the adult hospital to differ to that which she and her colleagues provide in paediatric care. These expected differences mean she is somewhat cautious in her assessment of the care provided in the adult environment:

> *I mean, it's one of these things that happen to folk and they don't particularly want, nobody ever wants to leave, em or, none of the parents ever want to leave, the kids, like I say, sometimes you know it's like, it's like water off a duck's back, em eh … but it's one of these things that has to be done and you know they'll go on, you know, when they, if they do come back and say, "Oh – adults, it's nothing like it was here," you know, they're, they're obviously eh, you know, they're probably looked after adequately but just not looked after em … you know, in the, in the same way that everybody knows you and you're, you're comfortable with the environment and em, it's a nice place to be.* (HCP 06, Case 06)

The findings in this section imply that it was rare for young people's and parents' expectations of adult care to be addressed at an individual, experiential level. It also appears that people's expectations of adult care were influenced by the planning and preparation they had available to them and in which they had engaged in the context of their transition experience. Those who had more negative expectations of adult care appeared in many senses less ready for the move to adult care.

7.5 A process of change

Many participants talked about other life events and experiences occurring simultaneously alongside their experience of the process of transition, with case note evidence reflecting these changes and co-occurring experiences to some extent, but with some degree of variability. For many young people, the physical transfer to adult care was a co-existing event alongside other changes in their life, such as starting university, leaving home or leaving school, and was therefore seen by many as one more marker of their rite of passage towards adulthood.

Transition to adulthood is associated with a number of major developmental changes and challenges, as young people are required to attain and develop various skills, competencies, values and attitudes during the period of adolescence (Zarrett and Eccles, 2006). The developmental period of adolescence is considered to be critical in terms of establishing health-related behaviours, both positive and negative, and both for young people who have been ill as a child or live with a chronic condition and those who are regarded to be typically developing (Holmbeck, 2002). Therefore, transition to adulthood is notable for many different reasons, including the notion that although young people in this age group share a number of common features, they are also somewhat disparate in terms of physical, emotional, and social maturity (Kelly, 2008).

Thus, the move from paediatric to adult cancer care was seen as a process of change for young people, parents and health care professionals, as much as the other events in their lives, particularly as across all such contexts, young people sought some degree of emancipation from their parents in light of their impending adulthood. However, differences in young people's experiences were noted. The sub-theme of 'Simultaneous life transitions' therefore emerged as a key element to explaining this process of change.

7.5.1 Simultaneous life transitions

Relative to the experience of transition, it seemed that the often much-desired emancipation was, on occasion, more challenging for some young people and parent

dyads than others. The individuality of people's illness experiences, in addition to the structure and nature of their relationships, appeared to be particularly influential from this perspective. There were occasions where parents had particular concerns in terms of honouring such developmental desires of their son or daughter as a result of their cancer experience, a feeling echoed on occasion by some young people. This point is best exemplified by the experiences of those in Case 12, Natalie, Sheila and HCP 12.

Diagnosed when she was 11 years old, Natalie lives with both cognitive and physical impairments as a result of the tumour and the associated treatments. Now nineteen, she seeks to do many of the things in life that her friends and others do at that age, with college attendance and an opportunity to work being priority areas for her. During her interview, Natalie discussed her experiences of further education thus far, detailing how she was unable to complete the course she had enrolled for as she found it impossible to complete the end of course examinations as she was required to rely on her memory in those situations. It was evident that pursuit of her further educational goals was something of clear value and importance to Natalie, but it seems that her wider illness experience has restricted this, and consequently, her future employment. Not only that, the extent of these cognitive impairments means other elements of Natalie's life have become very much defined by the challenges associated to these impairments. This was evident within her narrative as she recalled a recent incident in which she was mistaken for being heavily under the influence of alcohol and as a result denied access to a pub. In reality, she lives with impaired balance, as a result of her treatment for childhood cancer, but she was forced to explain this in a very public forum:

> *Natalie: It's … I even wish that I could, my balance was better that … I was in the, I was, I went up the town wi ma friends and eh I wisnae drunk at all, I had two drinks, I was wob-, because my balance I was wobbling, the bouncer was like, "You're not getting in here, you're too drunk," and I was like, "I'm not, I've got bad balance," I says, "I've only had two drinks," he was like, "Na, you're too drunk, you're not getting in here," I says, eh, I said, "I've had [diagnosis], I've, I've had can-, …" I said, "I've had cancer," I says, "And I've got bad*

balance," and eh, I showed him something, a pass or something it was, had my disability, he says, "What eh, what do you want me tae, do you want me to believe you or something, like?," em, "If you had cancer what are you no in a wheelchair fur?" … and then I, I was … 'cause I was wi ma cousin, she was going mental and then just, like, "I'm gonnae bloody kill you," she was going mental, she was like, "This is my cousin, she's had, and blah, blah …" I'm going, "Shut up [cousin's name], shut up," and I was away greetin' [crying], getting in a taxi, "Take me hame," I was like, "[cousin's name], hurry up and get in this taxi," …

Lisa: What was that like for you when that happened?

Natalie: Oh, it was horrible. I just … it's like telling the whole world, shoutin' it oot … there was hundreds oh people outside and you just, we were, we were sitting having an argument and then my cousin made it even worse by she was going mental at him.

Lisa: So it's outside wi the rest of the queue were there as well and you had to explain to everybody else?

Natalie: But like maist, maist oh them, but they were shouting out tae, "That's appalling," and everything … but I felt really stupid [slight pause].

Thus, whilst Natalie's impaired balance could be considered a physical long-term late effect of her treatment, as we see in the previous quote, this very much has psychosocial ramifications for her. The latter part of the quote, in which she recalls feeling "really stupid", poignantly reflects the reality of living with this consequence of her treatment, which, coupled with her challenges at college, mean she has had somewhat of a disrupted experience of young adulthood thus far. Evidence available in her case notes reflected some of the challenges she was experiencing associated to both her college attendance and her problems with her balance, but often there was only little insight as to how Natalie felt about such challenges, as there was a brief synopsis of Natalie's encounter with the nightclub bouncer she discussed in her interview. In her case notes, the following reflected how Natalie felt about experience:

This again caused Natalie some upset. (Paediatric case notes, Case 12)

As this excerpt illustrates, the individuality of Natalie's illness experience appears to have been particularly influential on various life events and changes she has experienced. Within the context of her experience of the process of transition from a health care perspective, her illness experience has also been a particular influencing factor, as this transition has been disrupted by the reliance and dependency she places on her mother in terms of her overall health care experience. As a consequence, Sheila has had a very active role in Natalie's health care and long-term follow-up care throughout the duration of their involvement with the paediatric hospital, and as she says, she will continue to do so for the foreseeable future in adult care, too:

> *Sheila: And I still go, even though she's a bit older because, mainly because oh her memory, 'cause Natalie forgets what they said to her and then sometimes she would pick things up wrong and get herself aw in a tizz aboot it so, at least if I'm there then I can explain it when we come hame and, sit doon and talk aboot it and think what's the best route.*
>
> *Lisa: And you think that'll continue when you got to [adult hospital]…*
>
> *Sheila: Yeah … mm-hmm, mm-hmm … aye it will. No just because I think I should go, I think Natalie wants me to go as well and, maybe if she had a, she's got a boyfriend but maybe if she had a husband or that then I would stop then eh, but until, as long as Natalie's living wi' me then I'll still go wi' her whenever she's got appointments …*

However, there was a sense from Natalie's perspective that moving to adult care could be the catalyst for her in terms of taking some control of her own health care, as she does not think she has had the opportunity thus far to engage in a consultation on her own. Yet, the daily challenges she faces with her memory do mean she has had to become more dependent on her mother than she would like for her age:

> *Lisa: Do you think it would be something that you would like to be able to do on your own at some stage … have those consultations with the doctors?*

> *Natalie: I would like it but then … I would like it but I know that I probably wouldnae be able to remember it. So it is, in a way it is a good thing that my mum's there because she can write these things doon … but sometimes it feels like, well I'm, I'm an adult and I should be like, be able to go in and speak to people and do stuff myself but I, I cannae 'cause I cannae remember it.*

This struggle, between striving for this independence and autonomy and recognising her own limitations, is one that pervades much of Natalie's discourse. There is a sense that she is frustrated with the presence of her long-term late effects, particularly the cognitive impairments, as these have hampered her progression in some ways, and now in a health care context, she still faces some of these challenges and these may only be exacerbated by the changes in the ethos of adult care. Natalie's developmental challenges were of concern to her nominated health care professional, HCP 12, as he was apprehensive of Natalie's abilities to cope in the adult sector, with the dependency she places on her mother and her developmental challenges potentially disrupting this experience for her:

> *I think there's a real risk of them feeling, you know, abandoned by [paediatric hospital] yeah … because I think she's mentally a lot younger than nineteen and I don't think she has really very, any real ability to separate herself from her mother, <u>despite</u> [original emphasis] the fact that she has a boyfriend and a sexual relationship and all the rest, which seems extraordinary but eh, she's still very attached to being with her mother, and the mother's very attached to [paediatric hospital] … so whether it'll work out or not, goodness knows – we've got to try.* (HCP 12, Case 12)

We can infer from HCP 12's narrative above that he is concerned about both Natalie and Sheila's readiness for moving to adult care, particularly in light of the dependency and attachment that appears to define not only their relationship with the paediatric hospital but also their relationship with each other. Nonetheless, Natalie recently attended the paediatric hospital for her long-term follow-up for the last time. There is a sense, though, that some of HCP 12's concerns are echoed by Sheila, discernible in

the following quote in which she reflects on her own readiness to leave the paediatric hospital. It seems that Sheila's readiness for this is tempered by the nature of the relationship she has with Natalie and the recognition of Natalie's development:

> *Sheila: Well … aye and no. As a parent I feel like obviously Natalie's still ma bairn and em, because we know everybody there and they know everything aboot her then aye I'm, I'm no, but the on the other hand she is an adult and she needs to go to that adult clinic and I suppose I need to really let her be an adult, eh?*
>
> *Lisa: What's that like for you to think that she's, she's an adult?*
>
> *Sheila: Well I, I do think oh her as an adult anyway, 'cause like, to be honest, we're really, we're really good friends as well as mum and daughter eh, we, we socialise together, we go oot together and go shopping together, we dae a lot together so – aye, I do treat her as an adult and we've always been really close so, it isnae hard for me to think … I dinnae feel like I'm losing my wee, my wee girl because she'll always be my girl, eh … regardless of what age she is and, and we are quite close so, I dinnae feel like, I dinnae want her to be an adult and move on.*

Sheila spoke elsewhere in her interview about the impact of Natalie's diagnosis and illness experience on her life now and her life as she was growing up, as she was unable to do many of the things her friends were doing. Thus, Natalie's interrupted path towards adulthood appears to have defined much of the latter stages of her childhood cancer experience. As we saw earlier in section 7.3.1, the longevity of the childhood cancer experience appears to be a significant contributory factor in defining people's experiences of readiness in the context of transition. From Natalie's perspective, her concerns surrounding her development towards adulthood featured prominently in her long-term follow-up consultations, some of which was captured in her case notes, as reflected in the following quote:

> *I thought Natalie was a bit low today. She was very tearful. She was bemoaning the fact that she is so childlike and wants to become an adult and be able to do things that normal adults do. She is starting to take a bit of exercise and has been swimming and walking.* (Paediatric Case Notes, Case 09)

Although it was recognised within Natalie's case notes and within the narrative of her nominated health care professional that she was struggling with the fractured nature of other life transitions intertwined with both her move from childhood to adulthood and the move from paediatric to adult care, Natalie's departure from paediatric care has proceeded.

In contrast to 19-year-old Natalie, 19-year-old Carla (Case 11) may be considered to have achieved what some may consider particular simultaneous life transitions, gradually emancipating herself from her parents by leaving home and living in University halls, with some time spent working and travelling without her parents prior to embarking on her University career. Furthermore, she had attended her first appointment in the adult sector alone, something that was novel for her, but which also made her feel 'grown up':

> *It was a bit strange, I was like, "Ooh! ... my mum's not here," but I was like, I suppose, "I don't need my mum here [laughs] – I'm 19!" [laughs], so yeah, em, but it was fine. It was actually kinda nice just to do it myself instead so I felt a bit more grown up rather than my mum taking me.* (Carla, young person, Case 11)

There is a sense that the novelty of this first time solo attendance, coupled with her realisation of her actual readiness to do so, was the catalyst for Carla to acknowledge that there had been some change in responsibility in her health care. Although somewhat tentative in considering herself ready for these changes, both her nominated health care professional and mother were more confident in their assumptions of Carla's readiness for moving to adult care, particularly in light of her positioning within the context of her other simultaneous life transitions. From HCP

11's perspective, Carla was very much ready to move on from the paediatric to the adult sector, particularly as she considered this experience to be very much embedded within other life course developments. The simultaneous nature of these transitions were also reflected in Carla's paediatric case notes, as it seemed that a more definitive discussion on the prospect of a move to adult care was held with Carla when she left school, as the following two extracts illustrate:

> *As Carla has now left school I discussed transfer to the long-term follow-up clinic at [adult hospital] and Carla is happy with this plan. An appointment will be sent out for [adult hospital] clinic in one year's time.* (Paediatric case notes, Case 11)

And, from the interview with HCP 11:

> *I think she's very well adjusted to what's gone on, em and didn't, didn't seem to be struggling at all with, with the transition, it was something she knew was going to happen, it was just part of her normal life-stage really, it was part of what was happening elsewhere in other things she was doing.* (HCP 11, Case 11)

Thus, moving from paediatric to adult care was very much seen as an extremely positive marker of success and survivorship for Carla from HCP 11's perspective. Indeed, the significance of a move such as this was considered by many other health care professionals in the study to be a particularly poignant indicator that young people were well enough and ready to move on in life. Such feelings were, in many senses, echoed by Carla's mother, Fiona, as she felt confident about Carla's move to adult care, particularly as she was aware of a notable positive change in Carla's maturity. For Fiona, this maturity was most evident, not only in the context of the two-year gap that had occurred between Carla's last paediatric and first adult appointment, due to appointment scheduling problems, but so, too, as a result of opportunities presented to Carla to explore other avenues in life during this period:

… perhaps because there was a bit of a gap between her last appointment and actually moving to [adult hospital]. She might not have been quite ready back then, but certainly by the time she actually had her appointment last week, she was more than ready to … to move on. She herself has matured a lot in the last two years … I mean, obviously she is in her first year at University, she had a gap year in between leaving school and starting University and she grew up a lot in that year… (Fiona, mother, Case 11)

7.6 Chapter summary

This chapter has explicated the fundamental defining features of the experience of readiness in the context of transition for the participants in this study. These features have been defined through intensive investigation of this orienting theme and the three main themes and associated sub-themes which were identified in the findings of this study. These main themes were: 'The experience of childhood cancer', 'Planning and preparation: transition or transfer' and 'A process of change'. Throughout this chapter, the multiple perspectives depicted the orienting theme and the associated main and sub-themes, allowing for an understanding of the experience of the process of transition, both within and between cases, to be generated. Moreover, the multiple perspectives allowed the experiences of the participants to be corroborated and contradicted, thereby increasing our understanding of the experiences of young people, their parents and health care professionals of the process of transition from paediatric to adult cancer services.

In the first instance, this chapter illustrated that people's experiences of readiness in the context of transition were variable. The findings have demonstrated that people's experiences in this regard are influenced by their experiences of childhood cancer, particularly so the longevity and uncertainty which defines this experience. In terms of longevity, it was revealed how those young people and parents who were able to consider the move to adult care as the catalyst for gaining some closure on their experience of childhood cancer were, in many ways, better ready for the move than those who perceived the move to be yet a further extension of their already

protracted experience. It has also been demonstrated in this chapter how the experience of childhood cancer is in many ways shrouded in uncertainty, not only in terms of young people's future health, but also in terms of the knowledge people have surrounding the need for a move to adult care.

Second, the findings have demonstrated that people's experiences of the planning and preparation surrounding their transition were variable. Again, such variability was shown to have a significant influence over people's experience of readiness, as the young people and parents for whom the physical move to adult care was the culmination of a planned process seemed more ready for this change than those who were suddenly confronted with this reality. Appropriate planning and preparation was also demonstrated to contribute significantly to the way in which people assimilated, and indeed were ready to assimilate, other changes and losses spurred by the process of transition, such as the removal of a level of safety and security afforded by the paediatric hospital and changes in relationships. Planning and preparation was also revealed to be crucial in terms of informing people's constructions of adult care and as such, their readiness for this new environment. A move to adult care engendered a number of changes for people, but it was evident that the extent of people's planning and preparation for such changes influenced their readiness in the context of their experience of transition.

Third, discourse from participants illustrated that transition from paediatric to adult care is intertwined with a process of change, as people experience a number of concurrent life transitions alongside their health care transition. The findings have been particularly demonstrative of the need to consider the wider context of the young person, their parent and their illness experience within the context of their experience of readiness and their experience of transition. Furthermore, these findings, and indeed the findings from the entire study, have highlighted the complexities associated with developing a meaningful understanding of the experience of transition.

As such, in the next chapter, the study research question shall be revisited to allow the findings of this study to be discussed in relation to relevant literature. Further, Chapter 8 will illustrate how understanding people's experience of readiness is influential on understanding people's experiences of the process of transition, and will explicate why the detailed understanding of the experiences generated in this study are important in terms of future transitional care planning for survivors of childhood cancer, their parents, health care professionals and supporting clinical information.

Chapter 8 Discussion and Conclusions

8.1 Introduction

The purpose of this PhD study was to consider the experiences of young people who are survivors of childhood cancer, their self-nominated parents and self-nominated key health care professionals of the process of transition from paediatric to adult cancer services, by manner of a qualitative case study in which interviews and case note reviews were conducted. The current chapter begins with a summary of the study findings, before a critical evaluation of the findings from the study with reference to wider literature and existing research. Next, the strengths and weaknesses associated to the strategy of inquiry adopted in this study are discussed. Lastly, prior to drawing final conclusions, a number of recommendations for future research and clinical practice are discussed, with particular reference to the findings of this study.

8.2 Summary of study findings

The findings from this study indicate that understanding the experience of readiness is central to understanding people's experiences of the process of transition, particularly as readiness needs to be defined by more than simple assessments of people's chronological aging or staging. Rather, as demonstrated in Figures 5, 6 and 7 on pages 172, 175 and 177 respectively, readiness needs also to embody people's illness experiences and their illness history. In particular, in the context of the current study, people's experiences of childhood cancer are particularly influential on their experiences of readiness – the findings demonstrate a clear need for readiness to account for an awareness of people's illness history, both in terms of planning and preparation during the process of transition, and in in terms of educating or re-educating people about their illness history as necessary. Furthermore, the findings from this study have demonstrated that the longevity of the illness experience and the uncertainty that surrounds this are particularly central in terms of understanding people's illness experiences. There is a need, therefore, for readiness assessments to extend beyond medically-orientated measures, such as young people's abilities to arrange and attend appointments on their own, take responsibility for management of

their medication, to more individualized, psychosocial, experiences-based assessments. Such assessments, therefore, should include consideration of the young person's ability to discuss competently what their diagnosis was, what treatments they received, what long-term late effects they live with now or may be susceptible to in the future, and how ready a young person is to acknowledge that their experience of childhood cancer continues beyond the boundaries of paediatric care. It was evident in the findings from this study that some young people saw the opportunity to leave paediatric care as a clear marker to move on from their childhood cancer experience, but for others, the move reiterated the longevity of this experience and in many ways hindered their readiness to move from paediatric to adult cancer services.

In addition, the findings demonstrated that the longevity of and the uncertainty associated to the experience of childhood cancer, as well as changes with and within relationships, the loss of the familiar that comes with a move from paediatric to adult cancer care and peoples' expectations of adult care, and their simultaneous life transitions, are all influential on people's experiences of readiness. Therefore, multi-dimensional considerations and assessments of people's readiness in the context of the process of transition are required.

Further, the findings demonstrate that parental assessments of readiness need also to be considered in the context of the process of transition. Young people have defaulted for so long to their parents for their health care information that parents too need to be prepared for the changes a move from paediatric to adult care involves in terms of their roles and associated responsibilities.

The study findings are discussed in greater depth and detail in section 8.3 that follows, by drawing on relevant literature.

8.3 Study findings in relation to relevant literature

In the previous section, the strengths and limitations of the strategy of inquiry adopted in this study were considered. There it was argued that a central strength of this study

is the multiple perspective, and multi-layered depiction of the experience of the process of transition of young people, parents, and health care professionals and clinical information afforded by the case study approach adopted in this study. In the following section, the centrality surrounding the nature of the multiple perspectives in this study continues by discussing the findings with reference to both the methodological and data sources employed, in relation to relevant literature and in relation to the research question posed:

- What are the experiences of young people who are survivors of childhood cancer, their self-nominated friends or family members and self-nominated health care professionals of the process of transition from paediatric to adult cancer services?

8.3.1 The experience of readiness in the context of transition

Based on the findings from this study, it can be argued that understanding people's experiences of readiness is crucial in terms of understanding their experiences of transition, especially so as this readiness was revealed to be multi-dimensional in nature. Moreover, the findings indicate that it is essential for transitional care research with survivors of childhood cancer to broaden its approach to acknowledge not only the various important components of this experience from their perspective, but so, too, the perspective of their parents, health care professionals and recorded clinical information. Only by doing so will we ensure that future research and transitional care service provision is fully reflective of the complexities associated with the experience of the health care transition of moving from child- to adult-centred health settings.

The findings from this study suggest that transitional care should better reflect the individuality of people's experiences. That is, rather than an approach to transition in which reaching a particular age or physical size is considered to be the most directive for instigating the physical move from paediatric to adult care, a more individualized approach which better reflects how ready individuals are in the context of their

childhood cancer experience, the planning and preparation surrounding their move, and the other simultaneous developmental transitions they may be experiencing, and their combined influence on people's readiness, is required. For example, the length of time since the young person has completed treatment, better acknowledgement of their illness, treatment and long-term late effects trajectory, and any additional challenges or experiences they have had along the way, should all be better considered within a transitional care context. Adopting this process would permit recognition of the variability in circumstances that may influence people's transition experiences and thus would ensure that the individuality of people's experiences is reflected within this context.

For example, like the findings of Cantrell and Conte (2009), for some of the young people in the current study, the paradox of being cured and being healed was evident, particularly in terms of the extent to which the cancer experience was a fundamental element of their identity. For many participants, the paradox of having completed their treatment for cancer and the cancer experience still remaining an essential part of their identity was evident. These findings resonate with those of Cantrell and Conte (2009), as they suggested that their young adult participants struggled to incorporate the loss and effects of treatment on their identity. These findings are particularly important as it seems that issues surrounding the impact on identity are as important for survivors diagnosed in young adulthood, like those in Cantrell and Conte's (2009) study, as for survivors of childhood cancer in the current study. This element is important within a transitional care context as many of the health care professionals interviewed regarded a move from paediatric care to be a positive marker of people's experiences, yet young people's narratives did at times indicate that many were, in the words of Cantrell and Conte (2009, p.320), "continuing to heal and suffer with the unintended consequences of cancer treatment", with some, like Steven and Natalie (cases 05 and 12, respectively) for example, appearing to consider themselves some distance away from being healed and whole.

In addition, the experiences of parents within a transitional care context should be given greater precedence than they currently are either across the literature or

throughout the process of transition in a health care context. The findings from this study indicate that transition can be a particularly challenging time for parents, too. This concurs with the findings of Casillas *et al.* (2010), who noted that transition was defined by a number of facilitators and barriers from parents' perspectives. However, the current study adds a further level of understanding to this by considering their experiences within the wider context of transition, particularly so their experiences of readiness. In addition, although parental challenges with transition and transfer were frequently acknowledged within the health care professional interviews in this study, this study has afforded an opportunity to better understand these challenges from the perspectives of the parents themselves. Moreover, a further understanding of parent's experiences within the context of having a child diagnosed with and surviving childhood cancer has also been imparted.

In addition, the parental self-nominations from each young person were indicative of the extent of the parents' involvement throughout young people's entire illness experiences. Parental experiences revealed that many were concerned about the decreasing level of involvement and inclusion they would have in their son's or daughter's health care within the context of moving to the adult sector, particularly as their previous involvement and inclusion had been, until this time, intensive and, for most, all-encompassing. Whilst narratives from the nominated health care professionals suggested both their awareness of such difficulties for the parents and a presumption that transition was commonly harder for parents than it was for young people, rarely was any specific support discussed that may have addressed the needs of these parents. Similarly, a paucity of associated information was available in the case notes, suggesting that parental needs rarely featured during long-term follow-up consultations. However, as the following quote from Patsy, the mother from Case 04 highlights, long-term parental needs are very real:

> *Cause you tend to remember mair aboot what went on in [paediatric hospital] than the young yins did … you know what I mean, it's just a big blur tae him – thank God [laughs], it's just the parents that end up absolute screwballs in't it? [laughs]*

The findings from this study also suggest that parents have a number of unmet needs within the context of the underpinning principles of transition. It would be anticipated that such needs would be addressed sequentially and simultaneously to young people during the transition process and so should have been addressed prior to the actual transfer itself, thereby preparing all concerned adequately for changes and losses such as those explicated previously in Chapter 7. Yet, in the current study, it appears parental needs were far from addressed in this context, as their experiences of readiness were, and professional responses to this, like young people's, variable. Despite this finding, the importance of parents within the paediatric health care team has been acknowledged previously, as has the need to understand the perceptions of parents and the ways these may differ from health care professionals (Sobo *et al.*, 2006). Such recognition is vital in the provision of patient-centred care (Sobo *et al.*, 2006), yet the lack of support for parents in the context of transition has been exemplified in this study.

Centralising young people in this research was important in light of the demonstrable paucity of experiences based and experiences driven, transition research in a cancer context to date, as discussed previously in Chapter 3. Crucially, the findings of this study have revealed the lack of detail and information surrounding young people's experiences of readiness and their wider experiences of the process of transition that are captured clinically. Young people's case notes indicated there was a lack of information recorded, which appears somewhat contradictory to recommended approaches to transition in a practice and policy context, which advocate for detailed transition plans to be recorded (Department of Health, 2008).

Indeed, in this study, the variability of information recorded across young people's case notes in relation to the level and detail of information surrounding their experiences of the process of transition was such that little consistency was noted between participants, even those recruited from the same site. Whilst variability in relation to recorded information about transitional care practices has been noted across hospital sites in the past (Mitchell *et al.*, 2005), such reflections have tended to

be driven from an organisational provision perspective, with little attention dedicated thus far to the extent to which recorded information is reflective of people's individual experiences. However, by incorporating the available evidence surrounding people's experiences of the process of transition in the current study into the conceptual understanding generated, tangible discrepancies between current service provision and young people's and parent's needs have been demonstrated.

There is a paucity of qualitative studies which have sought to explore the experiences of transition in a cancer care context, yet, studies of this nature, in which a variety of other illnesses and conditions feature prominently, are more readily available (Boyle *et al.*, 2001; Brumfield and Lansbury, 2004; McCurdy *et al.*, 2006; Shaw *et al.*, 2006b; Craig *et al.*, 2007; Fredericks *et al.*, 2011) Whilst the importance of illness and condition specifics must be regarded, such as those highlighted for survivors of childhood cancer in this study, some of the findings from the current study do still resonate with previous work. Thus, similar to the current study, Kirk (2008) considered that multiple and concurrent transitions occur in the lives of young people with complex health care needs and she, too, found that young people move on in particular ways as a result of the organisational (moved to adult services) and illness (moved to self-care and independence) transitions they experience.

The constructions and experiences of the health care professionals in this study cannot be discounted, for they too were central to informing the orienting construct in this study. Whilst many of these individuals spoke of young people appearing ready, primarily based on their physical appearance or age, it is suggested in this thesis that somewhat of a cultural shift is required to move beyond what would appear to be superficial assessments of readiness, to instead consider these within an individualized way, one which takes cognisance of the experience of young people and parents and of their readiness for transition.

As indicated in Chapter 7, section 7.3.2, the experiences of the participants in this study, particularly so young people and parents, afforded an insight into the concept of uncertainty and the ways in which this can taint their experience of childhood cancer,

particularly so during the period of survivorship. Such a finding certainly resonates with previous conceptualisations of uncertainty in the context of chronic illnesses – of which cancer can justifiably be considered – an acute phase precedes an extended period of life in which cancer may feature as a chronic illness or condition (Mishel, 1999). Thus, the concept of uncertainty is considered to be a constant experience within the context of chronic illness:

> *Due to the unpredictable and inconsistent symptom onset, continual questions about recurrence or exacerbation, and unknown future due to living with debilitating conditions.* (Mishel, 1999, p.269)

Therefore, much of what Mishel postulates has some semblance with the experiences of young people and parents in this study, particularly so as their narratives embodied both a fear of recurrence of the cancer and uncertainty as to the extent of any current or future onset long-term late effects. Certainly, in terms of this latter issue, fertility was one issue that featured prominently within many of the narratives. Concerns over potential future fertility have featured widely in the teenage and young adult cancer literature, both in terms of those who are survivors of childhood cancer and those who are survivors of cancer in adolescence and young adulthood (Brougham and Wallace, 2005; Oosterhuis *et al.*, 2008; Grinyer, 2009; Crawshaw and Sloper, 2010). The current study, however, has imparted valuable experiential insights into not only the extent of the uncertainty which surrounds this issue, but so, too, the importance of appropriate consultations in which the issue is broached and discussed, ensuring young people can assimilate such information into their lives.

Moreover, the findings from this study have highlighted the importance of considering not only the physical long-term late effects that young people experience within the context of their transition planning and preparation, but also the psychosocial consequences of cancer in childhood. The need to consider psychosocial late effects in survivors of childhood cancer is supported by Parry and Chesler (2005) as they identified that although young adult survivors of childhood cancer do thrive, are able to make meanings that can foster positive outcomes and are resilient, ongoing physical

and psychosocial concerns and worries are common amongst long-term survivors of childhood cancer, even those who are considered to be thriving. Yet, interview narratives and case note review data in this study indicated that psychosocial long-term late effects were rarely regarded to the same extent as physical long-term late effects in the context of the long-term follow-up appointments and transition experiences for many young people in this study. Rather, the focus tended to be much more on their physical health and physical outcomes. Such disparity is reinforced in light of a recent study conducted to re-engage survivors of childhood cancer lost to follow-up in late effects programmes by manner of a postal questionnaire (Edgar *et al.*, 2012). Although such a study highlighted that not only can non-attenders be re-engaged into active long-term follow-up through the use of a postal questionnaire, as 45% of respondants reported at least one late effect, the fact that only physical late effects were reported by the authors serves only to exacerbate the need to prioritize psychosocial elements associated to childhood cancer survivorship. The experiences of a number of young people in this study demonstrated the reality of living with a number of psychosocial late effects of treatment for childhood cancer, thereby supporting this call for greater prioritisation of these needs.

Whilst there is some consensus between the findings of this study and the current empirical base for conditions such as HIV (Wiener *et al.*, 2007), sickle cell disease (McPherson *et al.*, 2009), somatic chronic conditions or special health care needs (Sawicki *et al.*, 2011; van Staa *et al.*, 2011), liver and kidney transplant (Fredericks *et al.*, 2010; Gilleland *et al.*, 2012), and now cancer (Schwartz *et al.*, 2011), in which it has been noted that readiness is a central element of transition, there are a number of significant limitations in this body of evidence that should be considered in light of the findings from the current study. First, the existing body of evidence fails to acknowledge patient experience and almost consistently disregards the multiple realities of those who experience transition, and consequently their experiences of readiness. It can be argued that these multiple realities and patient experience have been neglected as a result of quantitative-based assessment tools primarily being used in these contexts, which tend to be developed with little or no patient involvement or informed without any qualitative explorations to consider the ways in which readiness

can be understood from the perspective of young people, their parents and health care professionals.

Therefore, the findings from this study are particularly important in light of earlier discussion in Chapter 3 of this thesis, which offered a critique of current definitions of transition. Drawing again on the definition of transition adopted in this study coined by Blum *et al.* (1993) and the further consensus statement coined by the American Academy of Paediatrics (2002) as cited previously in Chapter 3, section 3.3.1, readiness is not identified as a central element of transition within either of these contexts. So, despite the definition and associated goal of transition explicitly stating there is a need for the patient to be placed at the centre of the transition process, with a recognition of the changing needs of young people as they move from childhood to adulthood, the findings from this study suggest that scant regard is paid to young people's readiness for these multi-factorial changes within the context of current descriptions of health care transition. As was demonstrated in this study, rarely did the experiences of the young people reflect or embody this consensus statement in its entirety. Rather, there was a sense that often there was a lack of an individualized and planned approach to transition, in contrast to best practice suggested previously (American Academy of Pediatrics *et al.*, 2002; Royal College of Nursing, 2004; Royal College of Physicians of Edinburgh, 2008; American Academy of Pediatrics, 2009). Furthermore, in support of previous discussion in which transition readiness was argued as being not only multi-factorial but a multiple reality, the consensus fails to define or acknowledge the significance and readiness for transition from a parental or clinical perspective. However, as revealed in this study, considering parents' experiences of readiness, health care professionals' assessments of readiness, and the extent to which readiness is documented in the case notes, are equally important in generating an understanding of the experience of transition. Thus, it is argued that current definitions of transition need to evolve somewhat to ensure the holistic aspects of this experience are revered, both from the perspectives of young people and also from the multiple realities that contribute to constructions of understandings of this experience.

Linked to this conclusion is how this study has demonstrated the importance of considering and understanding patient experience in the context of transition. Previously, in Chapter 3 of this thesis, it was argued how little empirical evidence, with patient experience at its core, has informed many of the developments in transitional care research thus far. As a result, it can further be argued that the current accepted definition of transition is a step removed from this central element of patient experience. The current accepted definition, it can be argued, tends instead to prioritize service provision by focusing on the need for appropriate, continuous and interrupted service provision. Whilst in agreement that such arrangements are critical to ensure the seamlessness of the transition process, as these can help improve patient experience (While *et al.*, 2004), there is also a need to ensure we understand the patient within the complexities of their entire illness experience in the context of their transition. Moreover, an understanding such as this should be embedded within any transitional care planning, preparation and processes that occur. Consequently, the findings from this study suggest that current definitions of transition are not fully reflective of young people's, parents' and health care professionals' experiences of transition. Instead, a description which reflects the fundamental elements derived in this study, those of experiences and multiple realities, allows an extension to the goal of transition to be posited:

> *Transition in health care for young adults with special health care needs is a dynamic lifelong process that seeks to meet their individual needs as they move from childhood to adulthood. The goal is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood. It is patient-centred, and its cornerstones are flexibility, responsiveness, continuity, comprehensiveness, and coordination.* ***The process of transition must be defined by people's experiences of readiness. Readiness must, therefore, encompass and reflect the multi-dimensional components of the young person's and their parent's experiences of childhood cancer.***

Transitional care research conducted to date has tended to focus on the concerns of ensuring continuity in service provision (Forbes *et al.*, 2002; While *et al.*, 2004), whereas the current research has inverted these priorities and has derived a greater understanding and appreciation of the patient experience of this phenomenon. Preliminary results from one of the children and young people test and prototype teams within the Children and Young People Workstream of the National Cancer Survivorship Initiative (Morris and Tapp, 2012), have similarly prioritized patient experiences of the process of transition, with a number of important patient and parent experience components of transitional care for survivors of childhood cancer emerging in the work of Persaud and colleagues (2012). The work of Persaud *et al.* (2012) does complement the findings of the current study, particularly in light of the extent to which young people felt prepared for the process of transition. However, the multiple perspective approach adopted in the current study has added a further level of understanding of the experience of the process of transition, and a number of particularly insightful revelations, than that afforded in the Persaud *et al.* (2012) evaluation.

The findings from this study are congruent with those of Schwartz *et al*. (2011) in terms of their acknowledgement that transition readiness should account for factors beyond simply a patient's age and their knowledge of their illness and their health care associated skills. However, whilst these authors drew on social-ecological theories to inform their work, which is a useful addition to the findings of the current study, the prioritisation of the patient experience in the current study has been shown to be particularly advantageous, thus not only supports the findings of Schwartz *et al.* (2011) but also adds to the evidence surrounding the issue. In the USA, Schwartz and colleagues (2011) have recently argued that an increase in transition readiness is facilitated by a combination of assessment and transition planning, and the findings of the current study would support such a position. They further assume that transition readiness involves patients, parents and health care providers, an assumption further supported by the findings of this study. However, the findings from the current study advance the result of Schwartz *et al*.'s (2011) work, as the current study explored transition qualitatively, from a patient experience perspective, thereby adding a level

of understanding not possible through the use of their questionnaire, which appeared to have been completed by the researchers themselves, rather than the 100 consecutive young people attending the paediatric cancer survivorship clinic for an annual appointment the measure was piloted on (Schwartz *et al.*, 2011).

The results from the current study further support findings from a recent literature review conducted by Wang and her colleagues (Wang *et al.*, 2010). These authors proposed that Bronfenbrenner's (1979) ecological systems model provided an ideal theory in which to consider research and interventions relating to people's experiences of a health care transition (Wang *et al.*, 2010). The ecological systems theory is conceptualized in terms of hierarchical systems ranging from those closest to the person to those most remote, namely the microsystem, mesosystem, exosystem and macrosystem (Bronfenbrenner, 1979). Wang *et al.* (2010) considered this an appropriate model in light of not only the internal-external duality of disability and special health care needs, but also the multiple settings involved in transitions. Thus, following their review of 46 empirical studies, across a range of illness conditions (cancer featured in only one included paper), the authors called for a social-ecological approach to transition, particularly as they noted that a young person's proximal and furthest environmental systems have relevance to their transition experience. The findings of the current study indicate this would be a viable way to progress theoretical understandings of transition, given they have acknowledged to some degree the role of young people's microsystems (their family and health care providers), and exosystems (programmes of transition that would enable positive development) (Wang *et al.*, 2010). However, the findings from the current study would suggest that further dimensions should be incorporated into this social-ecological understanding. In particular, the experience of readiness has been demonstrated in this thesis as being central to people's experiences of transition, yet readiness was neglected within Wang and colleagues' (2010) considerations of young people's interactions with their environmental systems and the influence of these on their transition experiences.

8.3.2 Transition or transfer?

Throughout Chapters 6 and 7, it was highlighted how the planning and preparation that surrounded young people's experiences of transition in this study were somewhat variable, as there was a particular sense that some young people's experiences were more reflective of the process of transition than others. One reason posited as a contributory factor for such inconsistencies stem from the somewhat inherent inter-changeability of the terms 'transition' and 'transfer' within the clinical context. Raised previously in Chapter 3 as an issue within academic and policy-orientated literature, it is apparent that the terms 'transition' and 'transfer' fail also to be appropriately delineated within the clinical contexts considered in this study. Rather, it appears that the two terms have become hybridized, but this does little, as the following extract will demonstrate, to ensure the distinctive nature of the two components, transition and transfer, reflect the nature of people's experiences in this context. An example from Gary's (case 01) case notes particularly exemplifies this point:

> *We will see him back in our clinic next year and he is aware at this point it is likely that he will transfer to the adult services.* (Paediatric case notes, Case 01)

In addition, following a later consultation:

> *We plan now to transition him to the adult centre and his next appointment will be at [adult hospital] in one year's time. At his first clinic visit there we will do routine bloods and arrange a follow-up echo as I cannot see that he has had one performed since completing treatment. He is also aware that he will be referred to our Clinical Nurse Specialist*. (Paediatric case notes, Case 01)

From Gary's perspective, there was an indication that his experience was more aligned to a transition process, as he recalled being made aware of an eventual move to adult care some time before his actual last appointment at the paediatric hospital. However, Gary uses the term 'transaction', rather than transfer or transition, as documented in his case notes, when recounting this introduction to the process:

> *It was first discussed … not my last appointment but the appointment before that when I first saw Dr [name] at his, his well eh, one oh the doctors eh, who was treating me before that, well, yeah, eh, she basically said, "Oh, we've got the, the Dr [name] into, basically, he's basically dealing with the patients that trans- the transaction between child care and adult care, so if that's alright we'll just hand you over to him and see where things go," so, I was too, I was obviously a bit young, cause I was only 15 the first time I met him, but this year I feel I can go, kinda go, just go for it, I don't really see there's anything holding me back …* (Gary, young person, Case 01)

The findings from this study therefore raise questions about the extent to which the accepted definition of transition is both implemented and understood within the context of moving from paediatric to adult cancer services and in the context of people's experiences of this phenomenon.

Further, the term 'transition' was used on occasion by nominated health care professionals during their interviews and within the documented evidence within the case notes as demonstrated above, yet there is reasonable scope to question the appropriateness of the use of this term in these contexts. The collective findings from this study demonstrate that, in order to better understand young peoples and parents experiences, better clarification of both transition *and* transfer is required, to ensure their appropriate application. Such a call supports previous attempts to refine the meanings attributed to these terms (Schwartz *et al.*, 2011). The findings from this study, which are considered within the context of the orienting construct of 'the experience of readiness in the context of transition', do, however, prioritize both transfer and transition. The differences in these terms were discussed previously in Chapter 3, but the findings from this study, nonetheless, demonstrate that it is perfectly plausible to suggest that the term 'transition' is being used in a clinical context without cognisance of the complexities surrounding this ethos. Therefore, there is a need for far greater clinical recognition of the differences between the terms 'transition' and 'transfer', as the findings in this thesis have demonstrated that their inappropriate application can impact on people's experiences of the process of

transition. However, this thesis argues that until the issues surrounding either component are recognised and better understood, the two terms will continue to be used interchangeably. If such inappropriate reciprocity continues, there is a real danger that neither will fully represent nor acknowledge young people's and their parents' experiences of the process of or readiness for transition from paediatric to adult cancer care. Consequently, unmet needs could continue to be just that.

8.3.3 Models of transition

Chapter 3 of this thesis highlighted various models of transition, but noted that the empirical evidence base that had informed the development of the majority of these models was somewhat limited and weak. The findings from this study suggest that elements of these models are increasingly being implemented within a cancer context, but the principles of transition advocated by these models are yet to be fully implemented in this context. Only recently has there been progress to suggest that developed models are becoming more reflective of the needs of young people during transition (Gibson and Levitt, 2010a; Gibson and Levitt, 2010b).

Drawing on discussion in Chapter 3, in which models of transition were reviewed, the findings from this study suggest that the two paediatric sites from which patients were recruited in this study are implementing a hybrid of the sequential and developmental models of transition, to draw on the conceptual terms coined by Forbes *et al.* (2002) and While *et al.* (2004). However, this study demonstrates that neither model, nor a hybrid version, appears to be being implemented fully or consistently.

The findings from this study indicate that planning and preparation are key elements in helping to ensure people's readiness in the context of transition. The value of appropriate planning and preparation has been witnessed in previous transition research (Miles *et al.*, 2004) so the findings from this study support this body of work. A key element of the planning and preparation in the context of the current study was the loss of the familiar often engendered by a move from paediatric to adult care. This loss was, however, just one example of the differing perspectives of parents, health

professionals and young people in relation to the experience of transition in this study. Whilst there is some semblance of the elements of this loss, particularly in regards to the loss of health professional relationships, in other relevant transition literature (Brumfield and Lansbury, 2004; Miles *et al.*, 2004; Kirk, 2008), the novel multiple perspective approach adopted in this study permitted a deeper understanding of this issue. The narratives of participants in this study indicated that a sense of dislocation penetrated people's transition experiences; particularly so as much of what was familiar to them was lost or renegotiated as they moved on. Further, it was revealed that such losses for young people extend beyond losing their relationships with their health professionals, a prominent feature in previous work aforementioned. For example, as the narrative from Sarah in Case 06 clearly demonstrated, a loss of sense of self featured particularly prominently in her move from paediatric to adult cancer care. Indeed, the concept of loss of self has been much investigated previously, but predominately so in adults who are chronically ill (Charmaz, 1983; Charmaz, 1995).

Although Charmaz's work is concerned with the onset of chronic illness in adults, some of what she postulates may be helpful in explaining Sarah's loss. Two issues feature prominently in Charmaz's work (1983; 1995): the loss of self people experience and the need to adapt to impairment, both due to the onset of chronic illness in adulthood. Within this theoretical framework, Charmaz postulates that people who experience losses of self as consequences of their chronic illness may experience a diminished self. As is evident in Sarah's narrative, she spoke poignantly about losing part of herself, the part of herself defined by her illness, as a result of moving on from paediatric care. This resonates with the findings from Kralik and colleagues' (2006) who sought to examine the ways in which the term 'transition' has been used within health literature. They, too, found that challenges to self-identity occurred during the transition process, with the two concepts closely linked. However, in Sarah's case, such an inversion in terms of these challenges to self may, in part, be caused by her young age at the onset of her illness, as the forming of her identity may have been disrupted by the onset of her illness (Williams *et al.*, 2009) on the cusp of adolescence (she was diagnosed with leukaemia aged 11).

The multiple perspective approach adopted in this study also revealed a number of parental-specific losses. Parents' roles in their son or daughter's health care was set to change (for those interviewed following the last paediatric appointment), and in most cases had changed (for those interviewed following the first adult appointment). However, for some, particularly those interviewed following the last paediatric appointment, the reality of these changes, including reduced involvement in their son or daughter's health care, the loss of control in monitoring their health care, and less involvement and control over their life in general was only gradually becoming a reality for many. Therefore, these losses and the increasing autonomy of their son or daughter were not yet fully assimilated into some parents' lives, thus they were still processes through which they were working. The difficulties some parents may have with such aforementioned issues is acknowledged by Eiser (1993), as parents' involvement in treatment regimens and hospital appointments throughout their son's or daughter's course of life and illness is recognised.

The main theme of 'A process of change' derived in this study paid homage not only to the experiential nature of the process of transition from paediatric to adult cancer care, but also to simultaneous life transitions so representative of adolescence and young adulthood. Adolescence is a period characterized by change (Mahajan and Jenney, 2004), but for young people who have survived childhood cancer, such changes must be negotiated alongside illness-related concerns, including fear of relapse, insecurity and uncertainty for the future, loss of autonomy, damage to self-esteem and potentially distorted appearance and body image (Mahajan and Jenney, 2004). In this study, such illness concerns were considered not only from young people's perspectives, but also from those of parents and clinicians. For example, the findings from this study demonstrated the ways in which the childhood cancer experience continues to influence the lives of young people and their parents during the period of survivorship. These findings support previous work conducted by Kinahan and colleagues (2008), who explored parental involvement and concern with the health status of adult survivors of childhood cancer, from both the adult and parent perspectives. Although the mean age of the adult population in Kinahan *et al.*'s (2008) study was some ten years older than the sample of young people in the current

study, a number of similarities are noted between the findings of the two studies. As with the young people and parents in the current study, Kinahan *et al.* (2008) also noted the duality of the childhood cancer experience and the influence this has on the provision of appropriate survivorship care. Consequently, they, too, call for care for survivors of childhood cancer to encompass not only the individual, but also their parents/families and support systems. Such care, it is argued and supported in this thesis, is vital to ensure young people and parents are appropriately supported in the move towards adulthood and the move towards alternative models of long-term follow-up care.

This study further highlighted the significance of the provision of appropriate long-term follow-up care for young people who are survivors of childhood cancer. In particular, the study has illustrated that if young people are uncertain about their full illness experience, including diagnosis, treatments and long-term late effects, then issues surrounding patient education and knowledge within the context of this long-term follow-up care must also be considered. For example, narrative from Mark in Case 02 illustrated that he appeared to be somewhat unfamiliar with the term and purpose of long-term follow-up care. Whilst such a response was fortunately rare amongst the other young people, Mark's experience does highlight a number of particular issues that warrant acknowledgement within a transitional care context. Patient education and patient knowledge of their illness history, the purpose of long-term follow-up and why this dictates such care continues in their move from paediatric to adult care, should thus be prioritized. Not only do these elements have potential ramifications in terms of a person's ownership of their illness experience if uncertainty surrounds such issues, but so, too, it subjects current long-term follow-up and transitional care provision to some much warranted scrutiny, as it suggests that currently not all the needs of young people are being met by such arrangements. Therefore, the findings from this study further highlight the need to explore young people's experiences beyond "static" instances of where things may go wrong in relation to physical and psychosocial late effects (Dixon-Woods *et al.*, 2005, p.85). Using narrative-based approaches are, undoubtedly, central to exploring these experiences. This study has, therefore, valuably contributed to this evidence base.

Furthermore, the findings from this study were indicative of occasions where young people perceived learning for the first time of potential long-term late effects during either their last appointment at the paediatric hospital or their first appointment at the adult hospital. Hearing such news for the first time at that stage of the illness experience can hamper, for some, their abilities to move on from their childhood cancer experience, as potential long-term late effects, such as impaired fertility, higher risk of other cancers, earlier menopause or impaired organ abilities, may provide constant reminders of the childhood cancer experience. Thus, to both allow young people the opportunity to embed such health-related consequences into their lives and to be fully educated to permit more appropriate questioning and support within the adult sector, such issues could be raised within the context of long-term follow-up appointments earlier and more consistently. The findings from this study are, therefore, supportive of the recognised need to ensure a model of communication in which young people take the lead over their parents in communication interactions with their health care professionals actually exists (Gibson *et al.*, 2010). Thus, if the ethos and goal of transition posited by the American Academy of Paediatrics is to apply within a cancer care context, young people, and their parents, should be made aware of such issues prior to moving from paediatric to adult cancer care and professionals should ensure this understanding. Such an understanding is vital to allow young people to participate fully in decision making and health-related choices throughout their adult lives (Gibson *et al.*, 2010).

Thus, it is suggested that a conceptual framework is required which not only addresses issues around personal growth and development of the young person and reflects the changing role of the parent, as posited by Forbes *et al*. (2002) and While *et al*. (2004) in this model, but so, too, reflects the key experiences of transition as captured from the participants in this study. Numerous transition policy documents have been developed over recent years (McNamara-Goodger, 2005; Department of Health, 2006; Department of Health, 2007a; The Association for Children's Palliative Care, 2007; Department of Health, 2008; Royal College of Physicians of Edinburgh, 2008; The Scottish Government, 2008b), as explicated previously in Chapter 3 of this thesis.

However, the extent to which survivorship from childhood cancer is revered in such policy documents is limited and variable. Thus, a framework is required which will provide important additions to such discourse by not only addressing illness-related specifics, but also by highlighting experiential insights such as those afforded by the current study, thereby recognising the complexities of transition. As the findings from this study have revealed, readiness is at the core of people's experiences of transition, yet as has been demonstrated in this study, barely was readiness considered for young people and their parents. Therefore, it would be reasonable to suggest that more formal means of assessing this issue, at an individual level, is required, particularly within the context of long-term follow-up for survivors of childhood cancer. There would be real opportunity and viability in including/incorporating transition planning documentation within the context of long-term follow-up plans and treatment summaries, to ensure that young people's experiences and needs are reflected in any recorded documentation.

Finally, as demonstrated in this thesis, parents' readiness must also be considered within a transitional care context, particularly in recognition of the main themes identified in this study and by which their experiences can be understood. Therefore, it could be contended that parental specific needs within a transitional care context should be considered alongside those of their son or daughter and within any planning and preparation documentation.

8.4 Strengths and weaknesses of the strategy of inquiry adopted

A qualitative case study, in which individual interviews and case note documentary reviews were conducted, was adopted to obtain a rich and in-depth multiple perspective understanding of the uniqueness of people's experiences of transition. The current study was novel in such an approach, particularly within a cancer context. However, despite the robust and systematic nature of the methods employed in the current study, there were a number of challenges, too. These challenges are discussed and conclusions drawn, thereby demonstrating that although there were some

limitations in this study, a viable and novel design was adopted, which elicited new insights into the process of transition in a cancer context.

First, one of the considered strengths of this study lies in the timing of the interviews with participants; interviews were conducted within weeks of young people's last paediatric or first adult appointment. This is a particular strength of this study, as previous research has tended to employ retrospective designs in which young adults have been interviewed about their experiences of transition some fifteen to seventeen years following their actual transfer to adult care (Brumfield and Lansbury, 2004), or unspecified the stage of the transition process for the young person, at the time of participation in the study (Casillas *et al.*, 2010). In contrast, this study was able, by recruiting young people at either one of two key stages previously mentioned, to successfully capture people's experiences as close as possible to these stages of the transition process. The relevance of these experiences within the wider context of the process of transition can therefore be considered a significant contribution to the field, supporting the argument posited by Lewis (2003) that determining the appropriate timing of research and its associated data collection activities are dependent upon the priorities of the research and its objectives.

Recruitment difficulties dictated that single rather than repeated interviews were conducted with participants. This may be regarded a limitation of this study, given its focus on the process of the transition from paediatric to adult cancer care; that is to say, singular interviews may be considered contradictory in terms of exploring people's experiences of a process. However, the results have demonstrated that recruiting young people at either one of the aforementioned two key stages during the transition process still permitted a detailed exploration of people's experiences of the process of transition, for reasons that are twofold.

First of all, inconsistencies and inequity in terms of transitional care service provision were illustrated. For example, at times, a transfer-orientated approach defined people's experiences of transition, and consequently their experiences of readiness. However, this was often a negatively weighted relationship, as those young people

who had received less planning and preparation for the move, or struggled with the longevity and uncertainty surrounding their experience of childhood cancer or were experiencing challenges with the simultaneous life transitions, appeared less ready to move to adult care compared to those for whom clear elements of a transitional care process had been implemented. Second, recruiting young people at these two key stages of the transition process also meant that the interview approach afforded an opportunity to retrospectively explore the events that had led to and surrounded young people's actual transfer from paediatric to adult care.

A further strength of this study is the prioritisation of multiple perspectives. As revealed in Chapter 3, research involving interviews and case note reviews has rarely been used previously in a transition context and not at all in transition research with survivors of childhood cancer. This permitted the exploration of the experience of transition at multiple levels, thereby allowing the generation of an in-depth and multi-faceted understanding of the experience. Methodological pluralism such as this, McCulloch (2004) has argued, is crucial to allow different perspectives to be gleaned. Combining methodologies in this way has enhanced the study and has added a level of depth and detail to understanding the experience of the process of transition that would not have been afforded had either method been used in isolation.

Young people autonomously nominating both a friend or family member and a health care professional for interview, was also a particular strength of this study. Doing so permitted participation of those individuals whom young people considered the most important within the context of their lives and illness experiences. This strategy revealed that each young person nominated a parent for participation, due to their abiding presence throughout the illness experience, but also provided an insight into the variability of health care professional relationships embedded within young people's childhood cancer experiences. Whilst these latter nominations meant that conducting some of the health care professional interviews could be challenging as their involvement in the young person's transition process was sometimes minimal, the consistency of the parental nominations reinforced the peculiarities of the parent's transition experiences.

In that regard, the qualitative case study approach adopted provided a powerful way to generate an understanding of people's experiences of transition, especially as this is considered very much to be a human experience (Kralik *et al.*, 2006). Moreover, it could be argued that the data collected via each methodological and data source produced strong findings individually, but the power and strength of these was enhanced by the way in which they coalesced to lead to an in-depth and synchronous understanding of the experience of the process of transition. Corroboratory and contradictory within-case *and* between-case perspectives emerged, strengthening the understanding generated at both individual and collective case levels.

However, it could be considered a limitation of this study that the results are notable for a small sample of participants from Central Scotland and may not necessarily reflect potential differences in experiences, coupled with current transitional care clinical arrangements, in other areas of Scotland or beyond. Nonetheless, young people were recruited from different sites, with a number of similarities in their experiences, suggesting the tentative findings from this study warrant exploration in a wider participant sample. Yet, for some, the sample size of twelve young people may still be considered small, which may mean transferability of the findings is regarded as problematic. However, it is not the purpose of a qualitative case study to produce findings generalizable to an entire population, rather it is to demonstrate that the findings may be transferable to other contexts or may be used by others (Simons, 2009).

Similarly, although this study only explored the experiences of the process of transition in the context of a clinician led, institution-based model of follow-up, which may be considered a limitation in light of other models now developed (Gibson and Levitt, 2010a), the transferable nature of the findings are notable. It is argued that the experiential and exploratory nature of this study has provided a number of important insights into the experience of transition, irrespective of the model of long-term follow-up adopted. Further, the young people sample included people who had survived either a haematological (n=8) or an oncological (n=4) diagnosis, meaning that the experiences of the process of transition of both groups could be considered. Yet, it

is recognised that the slight bias in terms of haematological diagnoses may be considered a limitation by some, particularly in light of the varying long-term late effects that individuals within these two groups may experience. In addition, it may be considered a limitation that this study focused only on survivors of childhood cancer, and not young people across different stages of the childhood cancer experience. This means that whilst the concepts developed in this study are central to explaining and understanding the experiences of this particular population, they may not necessarily be transferable to other childhood cancer experience contexts.

The sample size of twelve has, however, ensured an in-depth understanding of the selected information-rich cases; considered to be an acceptable marker of validity and meaningfulness in qualitative inquiry (Patton, 2002). Further, as the actual sample size in this case study was reflective of the multiple perspectives embedded throughout this study, a total of 35 individuals were actually interviewed and 22 sets of case notes were subjected to documentary review. Indeed, sample size in qualitative research has been argued to refer not only to the number of individuals participating in any one study, but also to the number of interviews conducted, number of events sampled, or number of observations conducted (Sandelowski, 1995). The sample in this study was, therefore, considered adequate to ensure the research question was answered.

It was outlined in Chapter 5, section 5.3.5, previously, that the current study sought to recruit up to sixteen cases. In all actuality, twelve cases were recruited to this study, predominately due to the level of saturation the researcher believed she had reached within and across the recruited cases. Agreed methods for reaching data saturation in qualitative research are lacking (Francis *et al.*, 2009), but saturation is considered to be reached when nothing new is observed in newly sampled units or if enough can be made of data already coded to an existing category (Sandelowski, 1995). Recruitment of the 11th and 12th cases indicated to the researcher that no new and significant information was emerging. At that stage, recruiting a further four cases to contribute to the findings in conceptually diverse ways was considered unlikely.

In this study, knowledge was accumulated via the formation of informed and sophisticated constructions (Guba and Lincoln, 1998) of the experience of the process of transition. One caveat to this, however, is that the qualitative nature of this study means that the results are reflective of the researcher's own interpretations of the data. It is possible that a different researcher would generate study data different to those produced here and analyse them in such a way that a different set of findings would be revealed. This possibility may be considered a limitation of this study.

The exclusion of other sources of evidence and associated approaches to data collection, particularly observations or quantitative measures, may be regarded by some to be a methodological limitation of this study. Young people's clinical consultations may have provided observational opportunities, but in the context of the included data collection methods, the benefits of these supersede the exclusion of observations. For example, this study sought to understand people's constructions in order to understand their experiences of the process of transition, thus it was necessary to "enter into the other person's perspective" (Patton, 2002, p.341). To do this, people's thoughts and feelings had to be gathered and made explicit through qualitative interviews, as the meanings people attach to their constructions of what goes on in the world cannot be directly observed (Patton, 2002). Similarly, including quantitative-based data sources, such as a questionnaire or survey, for example, would have been somewhat inappropriate in this study. Some scholars debate the appropriateness of combining quantitative and qualitative methods, given their different epistemological, ontological and methodological underpinnings (Barbour, 1998), so the qualitative, exploratory approach adopted here was appropriate. Moreover, Chapter 3 revealed that quantitative-based transition studies thus far have tended to use measures which are neither directly developed from patient experience nor validated. Adopting a qualitative approach in this study has permitted the exploration and in-depth understanding of the experiences of the process of transition for survivors of childhood cancer and provided a significant addition to the field.

One final limitation that must be acknowledged is the maintenance of participants' local dialects, language and terminology throughout their cited quotations. The

adherence to this tenet may mean an understanding of those sections is more difficult for some readers, but writing them in this way ensured a true and accurate reflection of people's experiences as told to the researcher. The inclusion of the language notes and glossary on page 9 of this thesis should, however, have provided an appropriate point of reference for the reader should any of the dialectical terms appeared unrecognisable in their written format.

To summarize, despite the recognised limitations of this study, the strengths of the methodological approach adopted superseded the pitfalls. The epistemological stance adopted and the strategy of inquiry implemented facilitated the production of new evidence and further substantiated previous evidence from the transitional care field. Thus, having discussed the strengths and limitations of the strategy of inquiry adopted in this study, the next sections will focus on recommendations for future research and clinical practice.

8.5 Recommendations for future research

A number of potential avenues for future exploration have been identified in this study, both as a positive consequence of the methodological approach adopted and the centrality of the experiential understanding of the phenomenon of transition derived in this study. Thus, the approach adopted in this study and the findings have generated a number of implications for future research both in the domains of the process of transition from paediatric to adult cancer services and survivorship of childhood cancer.

Firstly, the insights afforded by this study have highlighted the multiplicity of experiences and their associated complexities that surround the process of transition from paediatric to adult cancer care. Such insights were revealed through individual interviews with participants, at particularly distinctive stages of the transition process, either just after their last paediatric or just after their first adult long-term follow-up appointment. However, to generate an understanding that further reflects the chronology of this experience, longitudinal studies, in which repeated interviews are

conducted with individuals, should be developed. Such studies should commence in paediatric care, recognising the longevity of the experience of both childhood cancer and survivorship, and continue beyond the period of initial attendance in the adult sector. The centrality of people's experiences would remain in work of this nature, as would a recognition of the multiple and simultaneous transitions through which one must navigate during a transition from paediatric to adult cancer care. Further, a longitudinal approach such as this would add appropriately to the rhetoric surrounding transfer and transition by clearly delineating one from another by tracking individuals over a period of time. Thus, the planning and preparation associated with the transition process and the actual physical transfer between services would be revealed. In so doing, further experiential evidence to help inform and improve transitional care service provision in a cancer care context would be unearthed.

The findings from this study are indicative of possible patterns worthy for exploration in future studies. As illustrated in Chapter 7, individuals' illness experience appeared to influence their experiences of the process of transition. For example, some of those young people who had had what may be considered to be a more complicated illness experience and were living with greater physical and psychosocial impairments, had a more interrupted path towards adult cancer care. However, due to the limited sample size, one cannot conclusively state that those who had a more interrupted path when leaving paediatric care experienced transition differently to their peers who had not had this experience. There is room, therefore, for future work to sample people purposively based on either their diagnostic group specifically or based on their long-term follow-up needs. The levels of long-term follow-up stratification proposed by SIGN (Scottish Intercollegiate Guidelines Network, 2004) could help guide this sample selection. Future research such as this is important, as although risk stratification for long-term follow-up and alternative models of care have been proposed previously (Wallace *et al.*, 2001), the experiences of young people in this study indicate, as does the literature (Jenney and Levitt, 2008), that such stratification has not yet been implemented universally.

As discussed in forthcoming section 8.6 Recommendations for Clinical Practice, the recent introduction of End of Treatment Summaries in Scotland provides an ideal opportunity to evaluate the use of these from an experiences perspective. Provision of these documents means this will be the first time young people will be provided with a formal summary of their illness experience. However, there is also an opportunity for these documents to include more information on a young person's experience of the transition process. The findings from the current study could be used to help inform the questions and information gathered in these summaries. An evaluation of the use of these documents from an experiential perspective should therefore be conducted.

Also, whilst this study did not explicitly seek to compare the transition experiences of young men and young women, future work may wish to do so. Whilst some discrete differences in the narratives between young men and young women were observed in this study, the small numbers of each gender (seven young men; five young women) prohibit any particular conclusions being drawn in this context. However, future work may wish to include gender as a fundamental variable in its sampling strategy, thereby adding to the discourse of the participants in this study.

In addition, two subsidiary but extremely prominent issues identified during recruitment in this study can also be viably posited as areas for future research. Two issues clearly related to transition, at times, challenged the recruitment of young people in this study. Firstly, as reflected previously in Chapter 6, a number of young people eligible to participate in this study asked to or elected to stay at the paediatric hospital for at least one more year/appointment, prior to moving to adult care, despite being considered developmentally ready by the clinician to leave. However, it appears little is known about this particular transition-related phenomenon and thus warrants exploration. Generating an understanding of this issue would, too, ensure any future planning and preparation for this transition is grounded in patient experience. Secondly, young people often did not attend their long-term follow-up appointment, particularly in the adult sector. Thus, there is a very real risk that this population will become 'lost to follow-up' (Kelnar and Wallace, 2004; Scottish Intercollegiate Guidelines Network, 2004). Although clinicians may hypothesis on reasons for this risk,

again, an in-depth understanding of these behaviours from a patient experience perspective is actually limited. Therefore, although potentially challenging from the perspective of recruitment, future work in this area is especially important, particularly so as evidence exists to suggest some people who fail to attend long-term follow-up appointments can be re-engaged with such services (Edgar *et al.*, 2012).

The findings from this study have also demonstrated that parents have a number of unmet needs, both within the context of the experience of the process of transition and within the wider context of having a child diagnosed with and survive cancer during childhood. Narratives from the parents in this study suggest that they too may experience a number of long-term psychosocial late effects of the experience of childhood cancer, as demonstrated in Patsy's quote earlier in section 8.3.1 of this chapter and as recognised in the literature (Dixon-Woods *et al.*, 2005). Thus, future research may wish to longitudinally explore the psychosocial experiences of survivorship from the perspective of parents and the influence these have on their readiness in the context of transition in light of the multi-dimensional nature of readiness as identified in this study. Furthermore, it was demonstrated in Chapters 6 and 7 that a number of parents believed they learned of new information surrounding their son or daughter's health care for the first time at the transfer stages of the transition process. Therefore, future research should also explore parents' understandings, alongside their son or daughter's understandings, of the young person's illness experience and illness history, as this may further influence parents' experiences of readiness. Opportunities would exist to do this concurrently within the context of long-term follow-up care and within the context of the process of transition, as such issues should be visited repeatedly. Further, as this study predominately explored the experiences of the process of transition of mothers, future research may wish to also consider the experiences of fathers. This would allow for any similarities or differences between the roles of mothers and fathers within young people's health care to emerge and may add a further level of understanding or new dimension to the experience of readiness so prevalent within this study.

In light of both the findings from this study and a recent systematic literature review, in which it was noted that diabetes mellitus was the only condition for which any evaluated transition care programme had achieved successful outcomes (Crowley *et al.*, 2011), there is a need to conduct a formal evaluation of transitional care programmes in a cancer context. However, unlike the studies reviewed by Crowley and colleagues, such an evaluation should incorporate patient experience and patient-reported outcomes, rather than focusing entirely on disease- and medical-based outcomes. Thus, a structured and systematic approach to transition is required to better prepare young people and parents for this process. A transition intervention should be developed in the context of young people's whole childhood cancer experience and be evaluated to ensure the improvement of young people's and parents' experiences of transition. Only then will we ensure that future developments to transitional care services and programmes meet the entirety of the needs of young people and parents moving from paediatric to adult cancer care services.

8.6 Recommendations for clinical practice

The qualitative approach adopted in this study has been crucial to ensure the generation of an understanding of people's experiences of the process of transition. The study and the associated findings are, therefore, supportive of previous calls for well-designed and well-conducted research to explore people's experiences of care (Entwistle, 2009), and research which will ensure the delivery of health care services that meet the actual and real, not perceived, needs of young people and their parents (Gibson and Twycross, 2008). In this regard, considering and understanding the multi-dimensional nature of the experience of readiness in the context of transition has a number of important implications for clinical practice.

Firstly, as a result of the timing of the interviews in this study, the importance of the provision of appropriate information to young people and their parents in the context of the planning and preparation surrounding their transition process was highlighted. For example, many of the young people and parents in this study talked of receiving little or no information about the adult hospital or young adult service to which they

were being transferred, prior to their departure from the paediatric hospital or prior to their first attendance there. This lack of information is reflected in the following quote from Helen, the mother from Case 09:

> *… but there's nothing [laughs], you don't even get, you don't even get an information sheet with the address, they just assumed I knew where [adult hospital] was, which I did, but em, there was no sort of, well here's information about [adult hospital], you know, whatever, just 'cause I worked there, but you know if, I'd just been somebody who didn't know it, it was like well, where's [adult hospital]?, What do they do at [adult hospital]?, Who's at [adult hospital]?, Who do you see?* (Helen, mother, Case 09)

Thus, there is a need for young people and parents to receive more structured information, both written and verbal, about both the new environment to which they will move and what the service entails. Whilst the provision of such documentation is regarded as a fundamental element of transition in the literature (American Academy of Pediatrics *et al.*, 2002; Rosen *et al.*, 2003), drawing on Helen's quote this appears not to be being implemented consistently in practice. Helen's quote also indicates there appears to be an assumption on the part of health care professionals that young people and parents will understand all that a geographic transfer such as this involves, but as Helen indicates, and as was supported by the experiences of other young people and parents, this assumption is unfounded. A structured transition plan should therefore be created, with information provision relating to the new service a central element of this. The provision of a planning document such as this would also limit the uncertainty some young people and parents expressed in regards to potential problems arising in the twelve-month period following their final appointment at the paediatric hospital and their first appointment at the adult hospital. Young people and parents interviewed after their last appointment at the paediatric hospital talked of being unsure about who they were required to contact in that period, should the need arise. In all actuality, many indicated they would be inclined to go back to the paediatric hospital for support or help if required, but they, in light of their recent departure from there, debated whether this would be the right thing to do. Thus,

ensuring information surrounding service provision elements such as these are clearly and repeatedly relayed to young people and parents during the process of transition will be crucial in contributing towards people's experiences of readiness. In addition, in terms of the organisational aspects which would influence people's experiences of readiness, the opportunity to have an orientation tour of the adult hospital should be consistently offered, a notion reflective of recommendations in previous studies which have explored transition for young people with other illnesses and conditions (McCurdy *et al.*, 2006). The importance of an opportunity like this is highlighted by young people's experiences in this study. An orientation pre-visit was provided to Daniel and was regarded as important to him. For Carla, on the other hand, moving to an adult cancer centre at that stage of her illness experience was revelatory, particularly in terms of the reality of cancer in adulthood she encountered in that new environment for the first time during her first appointment there.

Indeed, the experiences of Carla and others in this study indicate that the organisation and structure surrounding the location of the long-term follow-up clinics in adult settings warrant consideration. As Carla's narrative indicates, she was required to walk through a number of outpatient clinic areas at the adult hospital to attend her appointment. Although after passing through three or four clinics of people at different stages of their illness experiences and of different ages than she, she was able to find the young adult clinic which she was to attend, an opportunity exists to limit such additional stressors for young people at this point of transfer. The importance, therefore, of locating LTFU clinics for young people in a distinct area of the hospital, or in the first outpatient clinic area, is highlighted and should be considered in future developments of transitional care service provision.

The multiple-perspective, qualitative case study approach adopted in the current study also revealed how, at times, the experiences of young people and their parents were incongruent with clinical experiences and perspectives. Investigation of the clinical case note data was particularly important here as this illustrated the paucity with which young people's experiences drove their transitional care provision. Moreover, the information that was captured in the case notes rarely reflected young people's

perceptions of transition and often failed to acknowledge the individuality of their experience. Therefore, there is scope within the clinical setting for more rigorous, patient-centred information to be gathered, over a prolonged period of time to reflect the process nature of transition, in these case-notes. Doing so, it is argued, would better place patient experience at the heart of transitional care service provision.

In addition, such a lack of recorded information has important implications in terms of young people's continuity of care. Such continuity, it has been demonstrated in this thesis and supported by the literature (While *et al.*, 2004), is an important element of transitional care for young people and parents alike. However, such continuity may be compromised by the scant detail recorded in young people's case notes, particularly around their transition experience and in the context of any long-term late effects they live with. However, by documenting young people's experiences of transition in a more formal way, information surrounding their experiences of the process of transition would be substantially improved. This practice would allow a young person's illness experience to be captured in more detail, thereby allowing for transition planning and preparation to be addressed in such a way that their individual needs can be addressed and met.

Similarly, patient experience and an individualized approach to transition should be better recognised in terms of assessing patients' readiness to move on from the paediatric to the adult health sector. As demonstrated in this study, clinicians' assessment of patients' readiness for this move appears to be based more upon the chronological age and physical appearance of the young person, rather than a more individualized approach in which their unique needs may be assessed and managed. Assessment of this readiness appears to negate somewhat the illness experience of the young person, in terms of their diagnosis, illness trajectory and any long-term late effects they currently live with. However, as this study has demonstrated, through its prioritisation of narratives to interpret health care and its exploration of people's experiences (Ahlberg and Gibson, 2003), there is need to consider the important events in people's lives. This, Ahlberg and Gibson (2003) argue, is essential to ensure clinical practice can be enriched. Therefore, the findings from this study warrant

clinicians to consider the events in people's lives collectively during the course of the process of transition and its associated planning and preparation. The HEEADDSSS method of interviewing young people (Goldenring and Rosen, 2004), which focuses on Home, Education/employment, Eating, peer-group Activities, Drugs, Sexuality, Suicide/depression, and Safety, has been posited previously as an instrument for adolescent psychosocial assessment, so may offer one way to do consider the wider context of young people's lives. This tool has recently been used with young people requiring anticoagulant therapy (Jones *et al.*, 2012), to provide guidance for undertaking psychosocial assessments and to identify ongoing priority areas for education for the young person, thus the transferability of such a tool to a transitional care planning and process context should be noted. However, no such assessment tool appears to have been used with the young people in this study.

Better transition planning and preparation is required for survivors of childhood cancer. In this study, many young people and parents suggested that the prospect of moving to adult care should be introduced far earlier than it was for them for other young people and parents in the future. Young people in this study suggested that concrete discussions about the very real nature of this move occurring should begin from age 12 or 13 onwards. Whilst the health care professional interviews and case note reviews did indicate, that, at times, an eventual transfer to adult care had been discussed with the young person and their parent prior to their actual departure from paediatric care, it seemed that not all young people and parents understood the reality of this. Therefore, a consistent and structured approach to transition planning, aided by formal and recorded transition planning documentation, would ensure that the process of transition is far better reflected in clinical practice and would concur with the principles of transitional care provision (American Academy of Pediatrics *et al.*, 2002; Royal College of Nursing, 2004; Department of Health, 2006; Department of Health, 2008; Royal College of Physicians of Edinburgh, 2008). Moreover, fully embedding the principles of the process of transition in future service developments would better reflect the needs of young people and parents, based on the findings from this study.

The multiple-perspective approach adopted in this study afforded the opportunity to consider parental perspectives and experiences of transition. Resultantly, a number of parental-specific unmet needs within the context of transition, and indeed the wider childhood cancer experience, were revealed. Firstly, in terms of transition, some parents also spoke about the shock associated with learning their son or daughter had to leave the paediatric hospital to attend adult care. Some were under the impression that after the period of 'five years' clear', their son or daughter would no longer need to attend any long-term follow-up appointments. It appeared for some that this particular period was one upon which they focused, thus learning their son/daughter would indeed need to continue to attend such appointments was disruptive in many senses, as they had assimilated this former information into their lives over a number of years. Therefore, the longevity of long-term follow-up needs to be integrated into consultations throughout the childhood cancer experience and should be particularly re-visited on an ongoing basis during long-term follow-up appointments, both to raise awareness of and to ensure understanding of information they may have been told previously, but during a time of particular emotional turmoil.

In addition, many of the parents spoke about their anxiety surrounding the experience of having had a child diagnosed and treated for cancer. Although the anxiety did not appear to dominate their lives, in ways it did during the acute phases of their child's illness; for many, the anxiety they experienced now penetrated much of their experience during their child's survivorship thus far. This latter anxiety was caused by many of those illness-related concerns aforementioned and as explicated in Chapters 6 and 7. In particular, the uncertainty surrounding their son or daughter's future health and well-being was especially anxiety-provoking. Indeed, Dixon-Woods *et al*. (2003) found that the enduring threat represented by cancer to their child's future was particularly powerful for parents. Thus, parents may require particular support as their child moves through the traditional markers of survivorship, particularly those symbolic of the early years of survivorship, such as moving through to monthly, quarterly, six-monthly and eventually annual appointments until the longed for marker of their child being disease-free for a period of five years is reached. However, as the findings in this study demonstrate, parents may require particular support beyond this

'five years' clear' period, particularly as this had provided many with an erroneous end point to the experience. Thus, the reality of the longevity of the experience may warrant parental specific concerns to be addressed.

Finally, there is a need for young people to be provided with detailed, written information in relation not only to their transition and transfer, but also about their illness history and illness experience. Although work is ongoing in the context of long-term follow-up and long-term late effects to do this, with the recent introduction of End of Treatment Summaries in Scotland (The Scottish Government, 2012), this study has provided further support for the real need for young people to be educated and/or re-educated about their illness history and illness experience, particularly in light of the increasing responsibility for self-management that comes with a move to adult care.

8.7 Concluding remarks

This thesis has presented a detailed and in-depth understanding of the experiences of young people, their self-nominated parents and health care professionals of the process of transition from paediatric to adult cancer services, for long-term follow-up care. The thesis has proposed that understanding people's experiences of readiness is central to understanding people's experiences of transition and has paid particular regard to a number of key concepts which explain this orienting construct.

The findings of this PhD study indicate that patient experience needs to be better incorporated into and reflected in transitional care service provision. Conceptual advancements have been proposed, particularly so in terms of highlighting the need to consider patient experience and readiness, and it has been postulated that if these conceptual developments are considered in a synchronous manner with clinical service provision, this will ensure patient experience drives transitional care for future generations of young people who survive childhood cancer and their families who will experience the process of transition from paediatric to adult cancer care. In addition, the findings from this study viably add to the existing field of transition research generally, but most pertinently, pave the way for focused dialogue and action within

the context of transitional care for survivors of childhood cancer. Most certainly, the value of patient experience in future empirical and clinical developments in this context cannot be underestimated.

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Appendices

Appendix 1: Selected transition studies (non-cancer)

Qualitative Studies					
Author / Illness / Country	**Sample***	**Methods**	**Key results**	**Strengths**	**Weaknesses**
(Hauser and Dorn, 1999) Sickle Cell Disease USA	N=22 adolescents, mean age 16.2 years; N=22 parents; N=8 HCPs.	- Focus groups. N=4 adolescent, N=4 parents and N=1 HCP groups.	- Three main themes identified in adolescent and parent focus groups: Concerns, Expectations, Preparation Needs. - HCP groups: Different main themes identified - differences in child and adult care, transitioning experiences, barriers to transitioning, natural points of transitioning, desirable characteristics of a transitioning programme.	- Analysis from each participant group presented separately: allowed comparisons of perceptions and experiences. - Transitioning Framework recommended which presents an ecological perspective of transition and which should consider a holistic perception of adolescents. - Framework based on people's experiences.	- Adolescents' stage in the transition process unclear. - Planning discussions for transition with adolescents and clinical staff unclear. - Parental involvement in discussions unclear.
(Brumfield and Lansbury, 2004) Cystic Fibrosis	N=6 young adults, aged 19-34 years.	- Individual face to face in-depth interviews. - Retrospective one off interview.	- Four overarching factors which appeared to affect the experience of transition -paediatric care, adult care, elements of the transition programme & psychosocial factors.	- Qualitative approach allowed the individual experiences of transition to be explored. - Background overview of participants provided thorough short case history to set context for their experience.	- Time since transition - the two oldest participants moved to adult care 15-17 years prior to the study – reduces validity of some of the claims authors make about the transition

Australia			- Orientation tours of adult facilities experienced by 3 young adults – beneficial, particularly if toured more than 1 to promote choice & increase responsibility for own care.		experiences for this group as transition programmes and processes may developed in this period. - Large differences in transition time may have been problematic for recall issues in interviews. - Small sample size.
(Miles *et al.,* 2004) HIV-positive adolescents UK	N=7 adolescents, aged 16-22 years.	- Individual semi-structured interviews.	- Three phases of transition identified: 1) Preparation; 2) Actual transition; 3) Post-transition.	- Experiences of transition explored in depth and at individual level. - Future recommendations made – meet adult staff, tour of adult clinic, flexibility, continuity.	- Small sample size - Limited generalizability. - Interviews conducted with each participant 1-2yrs after their transition.
(Shaw *et al.,* 2004b) Juvenile Idiopathic Arthritis (JIA) UK	N=12 adolescents, aged 13-18 years; N=14 parents of adolescents; N=18 young adults, aged 19-30 years; N=9 parents	- Focus groups. - 11 focus groups held in 3 geographic regions of England. - Groups split into 4 and held	- Transitional care: participants consistently wanted a transitional care programme that is multi-dimensional, coordinated, supportive, developmentally and age-appropriate.	- Study unique as is the first controlled study of transitional care in a childhood-onset illness. - Including users of the service meant relevant needs identified from their own perceptions and experiences. - Range of geographic locations and experiences of services considered.	- High female presence in the young adult groups: potential limitation as authors report that males with JIA struggle more in adulthood with establishing relationships with people of opposite sex, but lack of exploration of their experiences in this study.

	of young adults.	in each region.			- No discussion of any age specific transition issues or needs.
(Reiss *et al.,* 2005) Disabilities and Special Health Care Needs (SHCN) USA	N=49 young adults, aged 13-37 years; N=44 family members; N=50 health care providers.	- Focus groups (n=30) and interviews (N=4).	- Four main overarching themes identified: Factors that affect Transition; Stages of Transition; Health Care Systems; Transition Narratives. - Two main factors found to affect transition: cognitive ability & progressive nature of disease.	- Considers perspectives of the process of transition of young adults, family members and health care providers. - Exploratory study: allows perspectives and experiences of participants to be considered.	- Sample of young adults broad: not focused on one diagnostic group. - Not clear what conditions recruited young adults live with and actual numbers of these in the study. - Range of conditions included (>30) limits claims that can be made about the transition experiences of different conditions and whether any specific issues are present for each group. - Under-representation of adult health care providers.
(McCurdy *et al.*, 2006) Organ Trans-plantation	N=17 young people, mean age 21.3 years. N=? HCPs	- Qualitative case study: N=4 focus groups with young people; individual interviews with	- Young people: Five elements of the transition process emerged - There to Here, Getting Ready, Frame of Mind, Making it Easier, Giving Back. - HCPs: Interviews revealed three main themes – People are	- Use of case study approach – can be used to discover individual perceptions. - Use of case study appropriate for exploratory work such as this. - Qualitative approach highlighted experiences of these young people.	- No information given on the number of health professionals interviewed - No rationale for why interviews conducted with health professionals and not focus groups.

Canada		HCPs; review of electronic documents.	Important, Expectations of Us, Information We Need.		- No reporting of any data from electronic records. - Data not triangulated.
(Visentin *et al.*, 2006) Type 1 Diabetes Australia	N=10 adolescents, aged 15-18 years. N=21 HCPs.	- Interviews.	- Few of the 10 adolescents actually reported concerns about the transition process – but they had limited understanding and knowledge about differences between paediatric and adult services. - HCPs were concerned that current systems were under-resourced and there was a lack of communication between some services.	- Exploratory study. - Considered process of transition from dual perspective.	- Parents perspectives not considered. - Small adolescent sample size. - Cites only one quote from an adolescent in merged reporting of findings.
(Kirk, 2008) Complex health care needs UK	N=28 young people, aged 8-19 years. N=9 parents, for young people with no verbal communic-ation.	-In-depth interviews.	- Young people reported experiencing multiple and co-occurring transitions. -Two main transitions identified were moving to adult services and moving to self-care and independence.	- Authors acknowledged variability in sample when reporting findings. - Considers the different transitions that are prevalent within young peoples' lives.	- Original study not focused on transition. - Lack of detail reported specific to the various conditions young people were living with.

Quantitative Studies					
(Boyle *et al.,* 2001) Cystic Fibrosis, USA	Pre-transition survey: N=52 CF patients, aged 18-63 years; N=38 parents. Post-transition survey: N=60 CF patients, 18-63 years.	- Survey.	- Pre-Transition Survey – highest reported areas of concern were potential exposure to infection, leaving paediatric physician, meeting new care team, potential for decrease in quality of care. - Post-Transition Survey – statistically significant decrease across all areas of concern reported at pre-transition, apart from 2 – concerns about being admitted to adult hospital facilities & potential exposure to infection.	- Tracks concerns and expectations of individuals pre- and post-transition from paediatric to adult CF care. - Identified a number of CF-specific issues that should be incorporated into transition programmes for young people with CF.	- Not clear if those surveyed post-transition were all the same people who were surveyed pre-transition. - No details on how they managed the tracking of participants to follow them up a year later. - Authors unable to calculate % of overlap between surveys due to anonymity. - Large variability in age ranges of CF patients.
(Farrant and Watson, 2004) Chronic illness New Zealand	N=53 young people, aged 13-18 years. N=39 young people had diabetes, N=14 had other chronic conditions; N=45 parents.	- Self-report questionnaire.	- Transition issues: 58% of young people could not identify who their health care provider would be in 5 years' time. - 16% of young people thought current paediatric provider would also be their future provider in adulthood. - 60% of parents identified that their child's future care would be provided by an adult specialist or a GP.	- Questionnaire developed following a literature review to identify key questionnaire items. - Use of questionnaire to explore what aspects of health services were valued was useful for comparisons within and between groups.	- Multiple testing of data – resulted in p value of <0.01 considered significant – but conservative interpretation of results. - Unable to explore issues specific to diagnostic groups based on the analyses conducted.

(Shaw *et al.,* 2004a) Juvenile Idiopathic Arthritis UK	Round 1: N=20 young people; N= 19 parents; N=43 HCPs. Round 2: N=16 young people; N=16 parents; N=42 HCPs.	- Delphi Study.	- Six areas identified as constituting best practice and feasibility of transitional care for young people with JIA. - Areas include: addressing young people's psychosocial and educational/vocational needs; an individualised approach; and honest explanations of the adolescent's condition and associated health care.	- Questionnaire tested for face validity. - Explored perceptions of young people, parents and health care professionals simultaneously. - Triangulation of findings with previous work to support validity of findings.	- Potential bias of 'user' members in panel, as they were identified from a list of members of a pre-existing support organisation. - Panel not homogenous.
(Remorino and Taylor, 2006) Kidney Transplant UK	N=16 patients, aged 17-20 at time of transfer.	- Evaluation - included case note review, clinician interview and patient satisfaction questionnaire.	- Case note review / clinician interview: After transition, 1 person was subjectively better in relation to adherence and control after transition, 9 people the same, 6 worse. - No differences found between those who attended transitional clinic in terms of adherence and those who did not. - Satisfaction Questionnaire - Timing of transfer was right for N=7 patients, N=4 timing wasn't right. Timing decided by clinician in N=6 cases, joint with clinician in N=5 cases.	- Multiple methods adopted to evaluate transition. - Triangulated data sources and evidence to provide an account of overall patient stability before and after transfer.	- Did not consider the experiences of parents or their satisfaction of transition programme. - No follow-up with the 10 patients who transferred to adult care outwith this hospital to compare experiences to those who had stayed within the same physical setting.

			- Satisfaction with transfer: went ok for N=9; N=2 thought it went badly or really badly.		
(Craig *et al.*, 2007) Cystic fibrosis Australia	Pre-transition: N=45 adolescents; N=64 parents. Post-transition N=27 adolescents; N=46 parents.	- Self-administered questionnaire.	- Pre-transition: 68.9% adolescents and parents concerned about losing contact with paediatric doctor. - Post-transition: 59.6% of participants concerned with not knowing the adult doctors. - Significant positive correlation between number of transition steps completed and overall transition description (r=0.494, n=47, p<0.01).	- Attempts to address gap of the need for more longitudinal research that considers concerns associated to transition over time.	- Pre and post transition groups not identical – not matched for age, gender or disease severity. - 6 year period for the post transition group but no rationale why. - No acknowledgement of potential recall biases.
(Wiener *et al.,* 2007) HIV USA.	N=12 adolescents infected with HIV, aged 9-25 years; N=39 caregivers.	Questionnaires at two timepoints: State/Trait Anxiety Inventory for Adults (Spielberger 1983); Transition Readiness Questionnaire (designed by the	- Transition Readiness – one third participants scored poor or moderate at T1; T2, over 50% scored in excellent range. - Between T1 & T2, significant increase in mean transition readiness scores & significant decrease in state anxiety. - Overall, poor readiness scores associated with increased state anxiety levels, greater number of years in paediatric treatment	- Needs of population explored, led to identified barriers associated to transition and creation of potential relevant interventions. - First report that describes a transition readiness process created to address a programme closure.	-No reliability or validity data of the transition readiness questionnaire as scale developed for this study. - No rationale provided as to the length of time between T1 & T2. Average 6.8 months apart.

		investigators).	programme & lack of confidence in home provider.		
(McPherson *et al.*, 2009) Sickle Cell Disease USA	N=70 adolescents, aged 14-20 years.	- Survey.	- Five components of transition readiness assessed. - Mean readiness scores low. - Results demonstrate poor preparation for transition to adult care.	- Data to help inform construction of transition programmes for this population.	- Selection bias: survey completed by small number of patient population. - Not clear how or rationale for selection of the five components of readiness that were assessed. - Force-choice responses.

Appendix 2: Teenager and young adult information sheet

Project Title
Transitioning between paediatric and adult cancer services: A qualitative exploration.

Introduction
Hi, my name is Lisa McCann and I'm a PhD student. You have been given this information sheet because you are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Please take as much time as you need to decide whether or not you wish to take part.

Why is this research being carried out?
The purpose of this research project is to learn about what it means for a teenager or young adult and their friend or family member to move from paediatric to adult cancer services. It is important to find out what this experience means to and for those young people who have been treated in the paediatric setting and will receive their long-term follow-up care in the adult setting. The way we plan to find out the views and experiences of teenagers and young adults and their friend or family member is by talking to them in an interview.

This study is expected to last for 6 months. However, you would only be involved for approximately 1 hour over this period or shorter if you decided to stop taking part. You are being asked to participate in 1 interview.

Why have I been asked to take part?
You have been asked to take part because you were diagnosed and treated for cancer and received care within the [hospital name] in [place] or [hospital name] in [place]. You were diagnosed at least 5 years ago and have just had your last follow-up appointment in the paediatric setting and will soon be moving to adult care or have just had your first follow-up appointment in the adult setting. Your experiences of this are important to me and I would like to hear what you have to say.

Do I have to take part?
No. It is up to you. If you do, you will be asked to sign a form giving your consent. If you are under 16 years old, you and your parent/guardian will be asked for consent. You will be given a copy of this information sheet and your signed form to keep. You are free to stop taking part at any time during the project without giving a reason.

What will taking part in this study involve?
If you might be interested in taking part in the project, I will tell you more about the study. If you agree to take part, you will meet with me, and I will ask you some questions. I will ask questions about your experiences of cancer, your experiences within the Paediatric Clinic, your thoughts about moving to the adult service and if you think there are differences between care in the paediatric and the adult setting. You will meet with me once. The meeting will take place in your home, or wherever is most convenient for you. The meeting will take approximately one hour of your time. The meeting will be audio recorded, to make sure there is an accurate record of the discussions. The recording will be stored securely at the University of Dundee and no-one outside the research team will have access to it.

I will also ask you if you would like to nominate a friend or family member to take part in the research too so I can learn about their experiences and perspectives of transition. It is up to you who you decide to nominate for participation. This person will be interviewed separately from you.

Will joining in help me?
I cannot promise the project will help you but the information I get might help other teenagers and young adults and their friends or family members who transition between services in the future.

Could anything go wrong during the project?
There is no risk involved in this project. If at anytime you don't want to do the research anymore just tell me. However, I know that talking about and reporting experiences of cancer can sometimes be upsetting. I would like to make sure you are feeling okay the day after we talk, so with your permission I will give you a call the day after we talk. If you are feeling upset then we can talk together about who else needs to know and how to let the clinical team know.

Will I be paid to take part?
Unfortunately I am unable to offer payment for participation in this research study. Participation is entirely voluntary.

Will my details be kept private if I take part? Will anyone else know I'm doing this?
All information which is collected about you during the course of the research will be kept strictly confidential. Your name and address will be removed from any papers to do with the research so that you cannot be recognised from it. Any quotes that we may use when we write up the research will not have your name on them.

If you are happy for your General Practitioner (GP) to be informed of your participation in this study, they will be sent a standard letter, telling him/her that you are taking part in this project.

What will happen to the results of the project?
I am conducting this study for a PhD degree. This means I will write a thesis about the research study and the findings and this piece of work will be assessed. I will also write publications about the work and may give presentations too. You will not be able to be identified in any report, publication or presentation.

Who is organising and funding the project?
The project is funded by the Chief Scientist Office at the Scottish Government. My supervisors and I work at the School of Nursing and Midwifery at the University of Dundee. I am also supervised by one of the Paediatric Oncologists at [hospital name] in [place].

Who has reviewed the research study?
Before any research project is allowed to happen, it has to be checked by a group of people called an Ethics Committee. They make sure that the research is OK to do. This project has been checked by the Department of Nursing and Midwifery Research Ethics Committee at the University of Stirling and NHS West of Scotland Research Ethics Committee 2.

Contact for further information

If you would like to talk to someone else before deciding to take part, or at any time during the project, you can contact me (Lisa McCann) at the School of Nursing and Midwifery, University of Dundee, by phoning 01382 384967 or by emailing l.z.mccann@dundee.ac.uk

Should you wish to contact somebody other than me, please contact Professor Yvonne Wengström, my main supervisor by emailing yvonne.wengstrom@ki.se or Professor Nora Kearney, my second supervisor on 01382 388532 or by emailing n.kearney@dundee.ac.uk

Thank you very much for taking the time to read this information.

Appendix 3: Friend/family member information sheet

Project Title
Transitioning between paediatric and adult cancer services: A qualitative exploration.

Introduction
Hi, my name is Lisa McCann and I'm a PhD student. You have been given this information sheet because you are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information. Please take as much time as you need to decide whether or not you wish to take part.

Why is this research being carried out?
The purpose of this research project is to learn about what it means for a teenager or young adult and their friend or family member to move from paediatric to adult cancer services. It is important to find out what this experience means to and for those young people and their friend or family member who have been treated in the paediatric setting and will receive their long-term follow-up care in the adult setting. The way we plan to find out the views and experiences of teenagers and young adults and their friend or family member is by talking to them in an interview.

This study is expected to last for 6 months. However, you would only be involved for approximately 1 hour over this period or shorter if you decided to stop taking part. You are being asked to participate in 1 interview.

Why have I been asked to take part?
You have been asked to take part because you have been nominated by a young person you know who was diagnosed and treated for cancer and received care within the Paediatric Oncology setting at [hospital name] or [hospital name]. The young person you know was diagnosed at least 5 years ago and has just had their last follow-up appointment in the paediatric setting or their first follow-up appointment in the adult setting. Your experiences and perceptions of this are important to me and I would like to hear what you have to say.

Do I have to take part?
No. It is up to you. If you do, you will be asked to sign a form giving your consent. If you are under 16 years old, you and your parent/guardian will be asked for consent. You will be given a copy of this information sheet and your signed form to keep. You are free to stop taking part at any time during the project without giving a reason.

What will taking part in this study involve?
If you might be interested in taking part in the project, I (Lisa) will tell you more about the study. If you agree to take part, you will meet with me separately from the person who nominated you and I will ask you some questions. I will ask questions about your experiences within [hospital name] in [place] or [hospital name] in [place], your thoughts about your young person moving to the adult service and if you think there are differences between care in the paediatric and the adult setting. You will meet with me once. The meeting will take place in your home, or wherever is most convenient for you. The meeting will take approximately one hour of your time. The meeting will be audio recorded, to make sure there is an accurate record of the discussion. The recording will be stored securely at the University of Dundee and no-one outside the research team will have access to it.

Will joining in help me?
I cannot promise the project will help you but the information we get might help other teenagers and young adults and their friend or family members who transition between services in the future.

Could anything go wrong during the project?
There is no risk involved in this project. If at anytime you don't want to do the research anymore just tell me. However, I know that talking about and reporting experiences of cancer can sometimes be upsetting.

Will I be paid to take part?
Unfortunately I am unable to offer payment for participation in this research study. Participation is entirely voluntary.

Will my details be kept private if I take part? Will anyone else know I'm doing this?
All information which is collected about you during the course of the research will be kept strictly confidential. Your name and address will be removed from any papers to do with the research so that you cannot be recognised from it. Any quotes that I may use when I write up the research will not have your name on them.

What will happen to the results of the project?
I am conducting this study for a PhD degree. This means I will write a thesis about the research study and the findings and this piece of work will be assessed. I will also write publications about the work and may give presentations too. You will not be able to be identified in any report, publication or presentation.

Who is organising and funding the project?
The project is funded by the Chief Scientist Office at the Scottish Government. My supervisors and I work at the School of Nursing and Midwifery at the University of Dundee. I am also supervised by one of the Paediatric Oncologists at Yorkhill Hospital, Glasgow.

Who has reviewed the research study?
Before any research project is allowed to happen, it has to be checked by a group of people called an Ethics Committee. They make sure that the research is OK to do. This project has been checked by the Department of Nursing and Midwifery Research Ethics Committee at the University of Stirling and NHS West of Scotland Research Ethics Committee 2.

Contact for further information
If you would like to talk to someone else before deciding to take part, or at any time during the project, you can contact me (Lisa McCann) at the School of Nursing and Midwifery, University of Dundee, by phoning 01382 384967 or by emailing l.z.mccann@dundee.ac.uk

Should you wish to contact somebody other than me, please contact Professor Yvonne Wengström, my main supervisor by emailing yvonne.wengstrom@ki.se or Professor Nora Kearney, my second supervisor on 01382 388532 or by emailing n.kearney@dundee.ac.uk

Thank you very much for taking the time to read this information.

Appendix 4: Teenager and young adult consent to participate form

Study Title: Transitioning between paediatric and adult cancer services: A qualitative exploration.

Researcher: Lisa McCann

Date Patient Approached……..

Patient Name ……

Date of Birth……..

Diagnosis…….

Patient Telephone Number……

Patient Address……

…….

…….

To be completed by the patient:

I provide my consent for the researcher (Lisa McCann) to have these contact details to contact me to confirm my participation in this study.

…….	**……**	**…….....**
Name	**Signature**	**Date**

Appendix 5: Health care professional information sheet

Project Title
Transitioning between paediatric and adult cancer services: A qualitative exploration.

Introduction
You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Please take as much time as you need to decide whether or not you wish to take part.

Why is this research being carried out?
The purpose of this research project is learn about what it means for a teenager or young adult and their friend or family member to move from paediatric to adult cancer services. It is important to find out what this experience means to and for those young people who have been treated in the paediatric setting and will receive their long-term follow-up care in the adult setting. It is also important to find out what practitioners experiences and perceptions are of the transition between services and the provision of long-term follow-up care.
The way we plan to find out the views, experiences and perceptions of practitioners is by talking to them in an interview.
The whole study is expected to last for 12 months. However, you would only be involved for approximately 1 hour or shorter if you decided to stop taking part.

Why have I been asked to take part?
You have been chosen because you have been identified as a practitioner who provides care and services to teenagers and young adults diagnosed with cancer and their friend or family member either in the paediatric and/or the adult care setting.

Do I have to take part?
You will be given time to consider taking part in this study. Participation is entirely voluntary. You will not be affected in any way if you decide not to take part.

If you decide to take part you will be given this information sheet to keep and will be asked to sign a consent form. You are free to withdraw at any time without giving a reason. You will not be affected in any way should you decide to withdraw from the study.

What will taking part in this study involve?
If you decide to take part in this study, you will be asked to participate in an interview with the researcher (Lisa McCann). I will ask questions about your experiences and perceptions of transitioning teenagers and young adults from paediatric cancer services to adult cancer services, arrangements for the provision of long-term follow-up care, what areas you think are working well within the context of this movement at the moment and what areas or things you think should be developed in the future. It is expected that it will take no longer than 20-30 minutes to take part in an interview. The meeting will take place at your work place, or wherever is most convenient for you. If you agree, we will record the interview, to make sure there is an accurate record of the discussion. Recordings will be stored securely at the University of Dundee and no-one outside the research team will have access to them.

What are the possible benefits of taking part?
The benefit of taking part as a professional will mean you will be able to contribute your perspectives of transitional care. It is hoped that this will ensure that future developments of services meet the needs of both patients and professionals.

What are the side effects or disadvantages of taking part in the study?
The disadvantages of the study are that you may have to take some time from your normal working day to participate in the interview.

Will I be paid to take part?
Unfortunately we are unable to offer payment for participation in this research study. Participation is entirely voluntary.

Will my details be kept private if I take part? Will anyone else know I'm doing this?
All information which is collected about you during the course of the research will be kept strictly confidential. Your name and address will be removed from any papers to do with the research so that you cannot be recognised from it. Any quotes that we may use when we write up the research will not have your name on them.

What will happen to the results of the project?
I am conducting this study for a PhD degree. This means I will write a thesis about the research study and the findings – this will be assessed. I will also write publications about the work and may give presentations too. You will not be able to be identified in any report, publication or presentation.

Who is organising and funding the project?
The project is funded by the Chief Scientist Office at the Scottish Government. My supervisors and I work at the School of Nursing and Midwifery at the University of Dundee. I am also supervised by one of the Paediatric Oncologists at Yorkhill Hospital in Glasgow

Who has reviewed the research study?
This project has been checked by the Department of Nursing and Midwifery Research Ethics Committee at the University of Stirling and NHS West of Scotland Research Ethics Committee 2.

Contact for further information
If you would like to talk to someone else before deciding to take part, or at any time during the project, you can contact me at the School of Nursing and Midwifery, University of Dundee, by phoning 01382 384967 or by emailing l.z.mccann@dundee.ac.uk

Should you wish to contact somebody other than me, please contact Professor Yvonne Wengström, my main supervisor by emailing yvonne.wengstrom@ki.se or Professor Nora Kearney, my second supervisor on 01382 388532 or by emailing n.kearney@dundee.ac.uk

Thank you very much for taking the time to read this information.

Appendix 6: Original ethics approval letter

West of Scotland Research Ethics Service
West of Scotland REC 2
Western Infirmary
Ground floor, Tennent Institute
38 Church Street
Glasgow
G11 6NT
e-mail: evelyn.macfadyen@ggc.scot.nhs.uk
Telephone: 0141-211-1722
Facsimile: 0141-211-1847

NHS
Greater Glasgow and Clyde

23 July 2009

Miss Lisa McCann
Cancer Care Care Research Centre
Department of Nursing and Midwifery
University of Stirling
Stirling
FK9 4LA

Dear Miss McCann

REC reference number:	**09/S0709/52**
Protocol number:	**Version 1 June 09**
Study Title:	**Transitioning between paediatric and adult cancer services: A qualitative exploration**

The Research Ethics Committee reviewed the above application at the meeting held on 21 July 2009. Thank you for attending to discuss the study.

Ethical Opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical Review of Research Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the Favourable Opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

1. The Committee would like the use of the term "significant other" to be changed to read "friend or family member".

2. The Committee suggested that a one hour interview with the Consultant is too long and suggested 10 to 20 minutes to be more appropriate.

Continued...../

23 July 2009

Letter to Miss Lisa McCann, University of Stirling...../

3. The Committee seek clarification as to whether Haematological Oncology patients are to be included in the study or not.

4. In the application form, QA6-2 it states that "no undue pressure will be put on people to participate or remain in the study if they wish to withdraw". The Committee seek assurance that no amount of pressure will be put on people to participate or remain in the study.

5. In the Information Sheets, in section entitled "Could anything go wrong during the project?", reference should be made to the fact that talking about and reporting experiences of cancer can potentially be distressing, as outlined in the study Protocol.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved Documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Significant Other draft Interview Topic Guide June 09 Interview Time Point A	Version 1	-
TYA draft Interview Topic Guide June 09 Interview Time Point C	Version 1	-
TYA draft Interview Topic Guide June 09 Interview Time point B	Version 1	-
TYA draft Interview Topic Guide June 09 Interview Time Point A	Version 1	-
CV - Miss L McCann	-	29 June 2009
Participant Consent Form: Practitioner Pilot and Main Study June 09	Version 1	-
Participant Consent Form: Significant Other Main Study June 09	Version 1	-

Continued...../

23 July 2009

Letter to Miss Lisa McCann, University of Stirling...../

Participant Consent Form: Significant Other Pilot Study June 09	Version 1	-
Participant Consent Form: TYA Main Study June 09	Version 1	-
Participant Consent Form: TYA Pilot Study June 09	Version 1	-
Participant Information Sheet: Practitioner Pilot Study June 09	Version 1	-
Participant Information Sheet: Significant Other Main Study	Version 1	June 09
Participant Information Sheet: Significant Other Pilot Study	Version 1	June 09
Participant Information Sheet: TYA Main Study June 09	Version 1	-
Participant Information Sheet: TYA Pilot Study June 09	Version 1	-
Compensation Arrangements	-	30 June 2009
Letter from Sponsor	-	30 June 2009
Covering Letter	-	30 June 2009
Protocol	Version 1	June 09
Investigator CV	-	1 July 2009
Application	Version1	1 July 2009
Practitioner draft Interview Topic Guide June 09	Version 1	-
Significant Other draft Interview Topic Guide June 09 Interview Time Point C	Version 1	-
Significant Other draft Interview Topic Guide June 09 Interview time point B	Version 1	-
GP Information Letter Main Study June 09	Version 1	-
GP Information Letter Pilot Study June 09	Version 1	-
Participant Information Sheet: Practitioner Main Study June 09	Version 1	-

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of Compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After Ethical Review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Continued...../

23 July 2009

Letter to Miss Lisa McCann, University of Stirling...../

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/S0709/52	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

Evelyn Macfadyen

Dr R Soutar
Alternate Vice-Chair

Enclosures: List of names and professions of members who were present at the meeting
"After ethical review – guidance for researchers"

Copy to: Prof Yvonne Wengstrom, Cancer Care Research Centre, University of Stirling
R&D Office, Tennent Institute

Appendix 7: Ethics approval letter following amendment

WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow and Clyde

West of Scotland REC 2
Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
Glasgow G11 6NT
www.nhsggc.org.uk

Miss Lisa McCann
University of Dundee
School of Nursing and Midwifery
City Campus
Airlie Place
Dundee DD1 4HJ

Date 15th November 2010
Your Ref
Our Ref
Direct line 0141 211 2123
Fax 0141 211 1847
E-mail Liz.Jamieson@ggc.scot.nhs.uk

Dear Miss McCann

Study title: **Transitioning between paediatric and adult cancer services: A qualitative exploration**
REC reference: **09/S0709/52**
Amendment number: **AM03/1**
Amendment date: **26 October 2010**

Thank you for submitting the above amendment, which was received on 03 November 2010. It is noted that this is a modification of an amendment previously rejected by the Committee (our letter of 26th October 2010refers).

The modified amendment was reviewed by the Sub Committee in correspondence. A list of the members who took part in the review is attached.

Ethical opinion

Favourable Opinion

I am pleased to confirm that the Committee has given a favourable ethical opinion of the modified amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved are:

Document	Version	Date
Protocol - tracked changes	Version 3 - October 2010	
Protocol	Version 3 - October 2010	
Modified Amendment	AM03/1	26 October 2010
Covering Letter		26 October 2010

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

09/S0709/52:	**Please quote this number on all correspondence**

Yours sincerely

Mrs Liz Jamieson
Committee Co-ordinator

Enclosures: List of names and professions of members who took part in the review

Copy to: Prof Yvonne Wengstrom
R&D – NHS Greater Glasgow & Clyde

Appendix 8: Teenager and young adult consent form

Identification Number:

Title of Project: Transitioning between paediatric and adult cancer services: A qualitative exploration.

Name of Researcher: Lisa McCann

1. I confirm that I have read and understand the information sheet (October 2010, version 3) for the above study. ☐
2. I confirm that I have discussed the study with those people whom I regard as appropriate and have had the opportunity to ask questions. ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
4. I understand that the study involves 1 interview and I understand I am under no obligation to complete the interview, as my participation is voluntary. ☐
5. I understand that sections of my medical notes may be looked at by a responsible individual from the University of Dundee or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records. ☐
6. I agree to the interview being audio recorded. It has been explained to me that recordings and transcriptions will be stored securely and that I will not be identified by anyone outside the research team. ☐
7. I agree to the use of anonymised quotes in reports and publications. ☐
8. I agree to my GP being notified by letter of my participation in this project. ☐
9. I agree to the researcher contacting a nominated health care professional for interview. ☐
10. I understand that the researcher may wish to contact me in the future to participate in further research studies she may conduct. I agree to that she can contact me to find out if I would like to participate in this work. ☐

Complete two copies: 1 for participant; 1 for researcher file

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Researcher	Date	Signature

Appendix 9: Teenager and young adult assent form

Identification Number:

Title of Project: Transitioning between paediatric and adult cancer services: A qualitative exploration.

Name of Researcher: Lisa McCann

Young person (under 16 or if unable, parent on their behalf) to circle all they agree with:

Have you read (or had read to you) about this project?	Yes/No
Has somebody else explained this project to you?	Yes/No
Do you understand what this project is about?	Yes/No
Have you asked all the questions you want?	Yes/No
Have you had your questions answered in a way you understand?	Yes/No
Do you understand it's OK to stop taking part at any time?	Yes/No
Are you happy to have the interview recorded?	Yes/No
Are you happy for the researcher to look at your medical notes?	Yes/No
Are you happy for your GP to know you have taken part in this study?	Yes/No
Are you happy for the researcher to contact a nominated health care professional for interview?	Yes/No
Do you understand that the researcher may use some of what you have said in her report, but will not include your name?	Yes/No
Are you happy for the researcher to contact you again in the future for any other work she might do, to see if you would like to take part?	Yes/No

Complete two copies: 1 for participant; 1 for researcher file

If you want to take part, you can write your name below
Your name
Date

Your parent / guardian needs to sign this form too:
Print Name
Sign
Date

The researcher who explained this project to you needs to sign too:
Print Name
Sign
Date

Appendix 10: Friend/family member consent form

Identification Number:

Title of Project: Transitioning between paediatric and adult cancer services: A qualitative exploration.

Name of Researcher: Lisa McCann

1. I confirm that I have read and understand the information sheet (October 2010, version 3) for the above study. ☐
2. I confirm that I have discussed the study with those people whom I regard as appropriate and have had the opportunity to ask questions. ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
4. I understand that the study involves 1 interview and I understand I am under no obligation to complete the interview, as my participation is voluntary. ☐
5. I agree to the interview being audio recorded. It has been explained to me that recordings and transcriptions will be stored securely and that I will not be identified by anyone outside the research team. ☐
6. I agree to the use of anonymised quotes in reports and publications. ☐
7. I understand that the researcher may wish to contact me in the future to participate in further research studies she may conduct. I agree to that she can contact me to find out if I would like to participate in this work. ☐

Complete two copies: 1 for participant; 1 for researcher file

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Researcher	Date	Signature

Appendix 11: Health care professional consent form

Identification Number:

Title of Project: Transitioning between paediatric and adult cancer services: A qualitative exploration.

Name of Researcher: Lisa McCann

1. I confirm that I have read and understand the information sheet (October 2010, version 3) for the above study. ☐
2. I confirm that I have discussed the study with those people whom I regard as appropriate and have had the opportunity to ask questions. ☐
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐
4. I agree to the interview being audio recorded. It has been explained to me that recordings and transcriptions will be stored securely and that I will not be identified by anyone outside the research team. ☐
5. I agree to the use of anonymised quotes in reports and publications. ☐

Complete two copies: 1 for participant; 1 for researcher file

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Researcher	Date	Signature

Appendix 12: Teenager and young adult interview topic guide

Standard Introduction:
I'm really interested in what it is like for people to move from paediatric to adult cancer care for their long-term follow-up. I'm here today to hear about your experiences of moving from [paediatric hospital] to [adult appointment]. You've just had your last/first appointment at [paediatric/adult hospital] and I'm really interested to hear what this was like for you, so:

WHAT WAS IT LIKE TO GO TO [PAEDIATRIC/ADULT HOSPITAL] FOR THE LAST/FIRST TIME?
Want to know about:

- What happened there? How it felt to go for last / first time?
- Differences between adult and paediatric hospital – why different?
- How it felt being in a different environment and with different staff?
- Support received – anyone else attend appointment?
- When was it first discussed that would be going to adult hospital for LTFU care?
- What did having this conversation feel like?
- Information provided by paediatric hospital about adult hospital – met anyone from adult hospital prior to going?
- Expected differences between paediatric and adult care?
- Developmental aspects – feel ready to be there? Why? What does this move signify? - Has this coincided with any other changes in their life?

SOME CONTEXT TO HEAR WHAT IT WAS LIKE WHEN HAD CANCER?
Want to know about:

- Age at diagnosis
- Diagnosis
- Any treatment memories
- Memories about paediatric hospital?
- Any attachment to paediatric hospital/staff?

DEVELOPMENTAL NEEDS – HOW ARE THESE ADDRESSED IN THE MOVE FROM PAEDIATRIC TO ADULT CARE?
Want to know about:

- independence/autonomy – if/how this was addressed during transition
- knowledge about illness history – knew everything by time left paediatric care?
- attachment / relationships – what support to end relationships with staff at paediatric hospital? What was it like to end these relationships?
  Changing nature of relationships with parents / family as got older and increased responsibility for own health care?

MAIN CONCERNS ABOUT HEALTH FOR THE FUTURE?
Want to know about:

- What these are and why
- How these are being addressed? Currently meeting needs?
- Support available?
- Physical issues – height / weight, diagnosed with cancer again, scars?
- Psychosocial issues – Fertility, Future relationships, fear of cancer recurrence

PROVISION OF LONG-TERM FOLLOW-UP CARE?
Want to know about:

- Understanding about why it is provided?
- Currently meeting needs?
- Support available?
- Any preferences for how would like this care to be provided?

General Closing:
Thank you for sharing your story and experiences with me. It's been really, really interesting to hear about. Is there anything else about your move for your follow-up care that you would like to talk to me about? Is there anything you feel we have missed or you would like to tell me? Thank you very much for your time today, I really do appreciate it.

Appendix 13: Friend/family member interview topic guide

Standard Introduction:
I'm really interested in what it is like for people to move from paediatric to adult cancer care for their long-term follow-up. I'm here today to hear about your experiences of moving from [paediatric hospital] to [adult appointment]. You've just had your last/first appointment at [paediatric/adult hospital] and I'm really interested to hear what this was like for you, so:

WHAT WAS IT LIKE TO GO TO [PAEDIATRIC/ADULT HOSPITAL] FOR THE LAST/FIRST TIME?
Want to know about:

- What happened there? How it felt to go for last / first time?
- Support received – anyone else attend appointment?
- When was it first discussed that would be going to adult hospital for LTFU care?
- What did having this conversation feel like?
- Who initiated these conversations?
- Information provided by paediatric hospital about adult hospital – met anyone from adult hospital prior to going?
- Developmental aspects – feel ready to leave? Why? What does this move signify? - -
- Has this coincided with any other changes in their life?
- Differences between adult and paediatric hospital – why different?
- Expected differences between paediatric and adult hospital – why different?

SOME CONTEXT TO HEAR WHAT IT WAS LIKE WHEN SON/DAUGHTER HAD CANCER?
Want to know about:

- Age at diagnosis
- Diagnosis
- Treatment memories
- Memories about paediatric hospital?
- Any attachment to paediatric hospital/staff?

DEVELOPMENTAL NEEDS – HOW ARE THESE ADDRESSED IN THE MOVE FROM PAEDIATRIC TO ADULT CARE?
Want to know about:

- independence/autonomy – if/how this was addressed during transition
- knowledge about illness history – knew everything by time left paediatric care?
- attachment / relationships – what support to end relationships with staff at paediatric hospital? What was it like to end these relationships?
  Changing nature of relationships with son/daughter as they got older/increased responsibility for own health care?

MAIN CONCERNS ABOUT HEALTH FOR THE FUTURE?
Want to know about:

- What these are and why
- How these are being addressed? Currently meeting needs?
- Support available?
- Physical issues – height / weight, diagnosed with cancer again, scars?
- Psychosocial issues – Fertility, Future relationships, fear of cancer recurrence

PROVISION OF LONG-TERM FOLLOW-UP CARE?
Want to know about:

- Understanding about why it is provided?
- Currently meeting needs?
- Support available?
- Any preferences for how would like this care to be provided?

General Closing:
Thank you for sharing your story and experiences with me. It's been really, really interesting to hear about. Is there anything else about your move for your follow-up care that you would like to talk to me about? Is there anything you feel we have missed or you would like to tell me? Thank you very much for your time today, I really do appreciate it.

Appendix 14: Health professional interview topic guide

AS YOU KNOW, YOU WERE NOMINATED BY X FOR PARTICIPATION IN THIS INTERVIEW. CAN YOU TELL ME WHY YOU THINK X WOULD HAVE NOMINATED YOU?

WHAT ROLE DID YOU PLAY IN X's CARE?
- how long involved? Explore their relationship to TYA. Explore their relationship to parent. What do these relationships mean to the health professional? Attached to family? Ending these relationships?

WHAT DO YOU THINK ABOUT X's MOVE TO ADULT CARE?
- what role did they play in the move? Did they think about the TYA? Did they think about the parent? Did they prepare the TYA for the move? Did they prepare the parent for the move? In what ways? How was the decision made it was time for X to leave? Any MDT discussions?

WHAT DO YOU THINK IS IMPORTANT IN X's LONG-TERM FOLLOW-UP CARE?
- long-term late effects? Provision of care?

General Closing:
Thank you for talking with me. It's been really interesting to hear about this transition case from your perspective. Is there anything else about X's experience and move to the adult hospital that you would like to talk to me about? Is there anything else in general about transition that would be useful for me to hear about? Thank you very much for your time today.

Appendix 15: Case note review data extraction template

TYA ID	ILLNESS CONTEXT	DEVELOPMENTAL ASPECTS	RELATIONSHIPS	TRANSITION	OTHER
CASE: DOB:	D: TX:				

Key: D = diagnosis DOB = date of birth Tx = treatment Chemo - chemotherapy

Appendix 16: Data matrix example

Role-Ordered Matrix - Case 06: The Experience of Childhood Cancer			
ROLE	**The experience of being diagnosed and treated for cancer as a child**	**Longevity of the childhood cancer experience**	**Striving for normality**
YP	Hasn't ever attended an appointment on her own, has always had her mum with her – both when a child and now as a teenager. Proud of herself for beating something a lot of people die from, but not sure she is able to let that part of her go yet, seems to be clinging onto the fact she had leukaemia as a child. ***Longevity of illness experience/readiness for next stage of her illness experience, knows she needs to move on from the experience***	Her cancer experience is always there, doesn't want to let it go as it has been a big part of her and who she is. Feels big part of her is in P hosp as spent so long there. Impact of LTLE pancreatitis for rest of her life and restrictions this will place on her - 'from being 10 and having no hair and getting stared at for being different and then having to be different again for the rest of your life'. LTLE discussions with new Dr – told her she 'should just be grateful that you are still here and it is not a serious matter'. Fears for future that if she has children they will get leukaemia and worries may not be able to have children. ***Longevity of illness experience and uncertainty of LTLE/ significance of illness experience in forming who she is/how were her concerns about being different for rest of her life addressed during transition?***	Knows she has a number of complications as a result of her treatment, Dr has told her, in the nicest possible way, she is "just unlucky". ***Longevity of illness experience/readiness to accept the fact she is "unlucky" impact this has on her being like her friends***
PARENT	Didn't often see the Consultant after her daughters treatment when they were attending for clinic appts as she was always on the ward 'looking after all the really, really sick children'. Moved through the clinics from weekly to monthly, to three	Daughter has pancreatitis as result of her tx's – is concerned about her daughter drinking alcohol, so wanted the Dr to reiterate the importance of not doing this to her daughter. Tries not to think of the strain the tx's have had on her daughters organs – 'I just want her to be ok – forever'. New Dr also brought up the issue of daughter's fertility for first time @ last P hosp appt – she found it quite emotional to hear about – doesn't know if daughter will be able to have	Daughter does say 'why me?' at times, particularly as she is living with a number of complications of the treatment. Talks to her daughter about the experience

	monthly to six monthly etc – struggled with this less frequent contact. Gets anxious in the lead up to the LTFU appt, in the week and few days before – 'I have a wee panic attack inside'. Also used to panic if had to wait in the waiting room for a long-time before being seen by the Dr. ***Longevity and uncertainty of experience – impact on readiness to leave the security and safety of this environment***	children in future. Wasn't sure if daughter was ready to hear that – 'it's quite a lot for a wee…a 17 year old to take on board'. Focused for so long on reaching the 5 year clear mark, didn't appreciate LTFU would be for so long – 'I just thought when X got the "all clear" 5 years down the line, that if, if it stayed about for 5 years, then that was her – *she was cured'.* ***LTLE – fertility – pancreatitis / uncertainty / longevity of illness experience / readiness of daughter to hear particular LTLE information***	she had through treatment compared to others, and the fact she is living with complications now that make it difficult for her daughter to be like her friends, in terms of drinking alcohol. ***Readiness to accept longevity of illness***
NOM PROF	Thinks people generally don't appreciate that 90 or 95% of young people diagnosed with leukaemia are going to be 'perfectly ok'. ***Survivorship – how define perfectly ok?***	Discussed the impact of the YP's pancreatitis, impact of this on her diet and debilitating impact on her life now – can't do what her peers do (clubbing, drinking etc), in the future 'she's not able to get away from it the same way as somebody else who's never had any of these side effects'. Will have to continue to live with the side effects of her tx as she gets older – thinks this may be easier for her when she is older rather than being a teenager, as everybody wants to drink now. ***LTLE – impact on life now and in future – longevity of illness – impact on readiness for transition***	See previous column – aware of impact of long-term late effects on the YP and how this prevents her being like her friends in some ways. ***Longevity of the illness experience***
CASE NOTES (P/A)	No data available	P notes following last appt with new Dr – has a normal menstrual cycle, fertility discussed, Dr reassured her unlikely fertility would have been affected by chemo – but don't know if she may experience an earlier menopause. Also she had recently had been admitted to hospital due to pancreatitis. ***LTLE – Impact on life now and in future – uncertainty***	No data available

Role-Ordered Matrix - Case 06: Experiences of relationships during childhood cancer			
ROLE	**Dependency**	**Attachment**	**Ending / Loss / Changing Nature of Relationships**
YP	Is very dependent on her mum for her health care –'I'm so dependent on my mum. I know I probably shouldn't 'cause I'm 17 but I'm so dependent on her being there'. Mother has been there for / with her for everything during her illness experience. Feels scared to leave P hosp as all her Drs are there who know her and her history – has met the new Dr but 'I don't *know* him'. Trusts all the Drs @ P hosp, feels safe & secure there, knows if anything happened to her, she would be 'in the best place possible.' ***Relationships – with mother and HCPs – impact of illness on these relationships (security / dependency) – how changing nature addressed during transition though? Impact on readiness to leave?***	Felt attached to P hosp, even though it was a building – 'it was like a friend because you are always there and you know or you'd always have to think about it'. Also felt attached and had a good relationship with some of the staff, especially her key nurse when she was being treated. ***Relationship with P hosp & staff/longevity of experience – readiness to leave these behind? Planning and preparation during transition to do so?***	Doesn't know new Dr yet so thinks it will take her longer to open up to him about anything that worries her. First time met him was first time conversation has been directed at her @ an appt – this was scary. Scared to go into appts on own @ A hosp – knows needs to push self and be mature – but scares her – but thinks she might be embarrassed if her mum is with her @ A hosp – 'I'm being moved on to the [A hosp] for a reason because I am old enough'. Says not too upset about leaving the nurses @ P hosp – 'at the end of the day I'm just another patient that's came in and out' and they have patients in there who they are helping. ***Developmental changes – changes in relationships and roles within those/ relationships with professionals – trust (worrying about establishing this)/ending relationships – coping mechanism as talks elsewhere about being worried to leave these behind.***
PARENT	Says P hosp was a 'security blanket' – been there for 8 years, knows all the staff, had lots of support from them, now	Thinks of the staff @ P hosp very fondly and will continue to do so now they have left, but wouldn't	Her role within daughter's healthcare relationship is changing – usually talks for her daughter, but @ last appt @ P hosp,

	going to 'an unknown territory'. P hosp special & security blanket - 'it's…where they, I suppose Dr X got her better and saved her life so you know to me, that was quite a special place'. Staff also made her feel secure, they knew what they were doing & were doing everything they possibly could to help her daughter. Relationship with same member of staff important, felt she could talk to them about anything worrying her. When daughter drank alcohol and ended up in hospital, she was very disappointed 'they saved her life once and then she went and had a drink'. ***Relationships - Security / safety / but loss of these now / ready to leave the security blanket behind? Planning and preparation***	expect to keep in contact with any of them now – 'cause they are professional people at the end of the day and they're not supposed to get that…you're not supposed to get that close to a patient, so yeah I wouldn't put them in that position'. Was wary of seeing new Dr for first time as knew previous Dr very well and felt comfortable being able to talk to her – but didn't feel she could question the decision as 'I'm only a mum. Who am I to go in and say "well actually no, I want to see…" ***Relationships – parents with HCPs / longevity of experience / involvement of parents – wouldn't question the decision / impact on readiness for transition?***	Dr directed all the conversation at her daughter – found this strange. Went up to the ward to say goodbye to staff @ last appt @ P hosp – staff were sad, daughter was sad saying goodbye. Wasn't aware this was the last appt so would have taken them chocolates to say thank you if had known. Sad to think the of this ending of these relationships – staff had been a big part of their life for so long – all of a sudden have nothing more to do with them. Is emotional about changing nature of her role within daughters health care – out of her control now – sign that her daughter doesn't need her anymore. ***Relationships - loss / planning and preparation – to be better ready for the loss and to say goodbye / longevity of experience***
NOM PROF	Thinks she got on very well with the YP & her mother – they all had a very good rapport. YP & her mother would often go up and see the Dr if they were attending appts elsewhere in the hospital & if YP in another ward due to pancreatitis, the Dr would always make a point of going to see her. Dr had input into the YP's care right through from tx to LTFU. Thinks	Says gets closer to some patients and their parents than others – 'everybody's got their, if you like their favourites, kind of idea'. Would know she was attached to a family by the rapport she has with the family and how relaxed they are together. ***Significance of relationships with***	Fact no longer having any input into YP's care is 'just part and parcel of what goes on, that's just life and is just things moving on'. Relationships with YP & families often brought to a natural close due to the frequency of the LTFU appts – 'you're sort of weaned into it, it's not that they're all here today and tomorrow you don't ever see them again, you're kind of

	YP's mum really liked attending P hosp 'it's just because they've been coming for *such* a long time'. Recognises that some families can become very dependent on P hosp and thinks 'kids are often better able to leave than the parents are' due to the relationships the parents establish with the staff. ***Longevity of experience / longevity of relationships / readiness to leave the place and people behind? How incorporated into transition planning and preparation?***	***families from professional perspective***	weaned into it'. But doesn't think they as professionals particularly need to be weaned into ending the relationships because 'we're professionals and you do know for the most part that they're leaving'. ***Planning / Preparation from professional perspective – their awareness of the ultimate endpoint helps the process of ending relationships?***
CASE NOTES (P/A)	No data available	No data available	No data available

Role-Ordered Matrix - Case 06 Developmental experiences in the context of transition			
ROLE	**Simultaneous Life Transitions**	**Independence and Autonomy**	**Teenage Behaviours**
YP	Realising that she will have to go to A hosp on her own is sad in many ways as it makes her realise that she's 'not a wee child anymore'. Wants to be treated like a grown up, but also wants to be treated like a young person at the same time – would rather it was a bit of both. Would be nice to be thought of as an older woman in relation to her health care – obviously tries to look older when goes out – but would still like to be treated in some respects like 'that kinda younger person in me but also treating me like the older person that they want me to be'. Acknowledges various things that change when you turn 18, particularly being treated like an adult. ***Developmental changes – moving to adulthood – readiness for this / Significance transition to A hosp means in relation to her growing up***	Last appt at P hosp was first time her mum hasn't been addressed directly or spoken to in the consultation - gave her a bit of a fright initially as this hadn't happened before, all of consultation was directed at her. Found this very different as is so used to the two of them being spoken to. ***Readiness for this change in appointment style / role in health care?***	Knows she can't ever drink alcohol – if she does, high possibility could end up seriously ill or dying due to pancreatitis. Also has to really watch her diet – has to watch what she eats and drinks. ***LTLE – impact on developmental behaviours / longevity of illness experience***
PARENT	Thinks her daughter is a very young 17 and half year old – but realises that a lot of things are going to change in her daughter's life soon – leaving school, starting university, possibly leaving home, leaving P hosp. So from her perspective as the mother 'there's lots of things going on in my life that's… "oh my goodness! – *my baby!"* ***Simultaneous life transitions – impact on and changes to relationship and role in daughters life***	See previous column.	Knows her daughter shouldn't be drinking as she is only 17, but knows her daughter has been struggling with this a lot recently as is at the stage of going to parties. Daughter struggles with accepting her pancreatitis issues – often asks 'why me'. Wanted someone from the hospital to stress the importance of this to her daughter –

			wanted the Dr to reiterate what she had been telling her daughter. ***LTLE – impact on developmental behaviours / longevity of illness experience***
NOM PROF	Thinks the YP knew a lot about what was going on in terms of her health care – 'she probably knew what was, you know what you would think would be appropriate for somebody you know, her age'. Thought the YP was also prepared, vocally at least, to take more risks than her mum would have wanted her to. ***Developmental progression / readiness***	Thought the YP was 'quite spunky' so this and the fact she could be little 'belligerent' at times is what got the YP through her experience. ***TYA's personality***	See longevity of childhood cancer experience column in 'The experience of childhood cancer' matrix.
CASE NOTES (P/A)	Letter in P notes that YP was in 3rd year @ High School, having no problems at school, had regular periods, enjoys dancing and going to the gym. ***General life transition information***	No data available	Letter in A notes following last appt @ P hosp 'she is aware she should not take alcohol, however, this causes her significant social distress and we discussed this at length in the clinic'. Letter in P notes she is 'doing very well in resistant to peer pressure to take alcohol again'. ***LTLE – impact on teenage behaviours / longevity***